CAREGIVER PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: NEED ASSESSMENT, MODEL TESTING, AND INTERVENTION STUDIES

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ABSTRACT

CAREGIVER PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: NEED ASSESSMENT, MODEL TESTING, AND INTERVENTION STUDIES

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The aim of the present thesis was to examine the predictors of well-being in caregivers of children with autism spectrum disorder and to develop a group intervention program for these caregivers. The current thesis is composed of three interrelated studies, whose aims were (1) to determine the problems of caregivers of autism spectrum disorder, (2) to reveal the predictors of caregiver well-being by using the integrative coping model of Holahan and Moos (2007), and (3) to develop and implement a group intervention program. Study 1 examined subjective experiences of the caregivers of children with autism spectrum disorder. The identified themes were insufficient knowledge, emotions, social support, and change. At Study 2, five hierarchical regression analyses were performed to reveal the predictors of depressive symptoms, positive affect, negative affect, and well-being indicators. Study 3, including development and implementing a group intervention program, was based on the findings of Study 1. Study 3 was conducted with 6 participants and findings revealed that after the intervention program, positive affects scores of caregivers as well as the well-being indicators were significantly increased as compared to their reports before the intervention. The possible explanations for and the implications of findings; and the limitations of these three interrelated studies were discussed. Overall, this thesis examined the factors associated with caregiving experiences of parents of children with autism spectrum disorder by performing need assessment, qualitative and quantitative studies; and it shed light on important factors in the development of an intervention program for caregivers.

Keywords. Caregiver, autism spectrum disorder, ASD, intervention, adaptation, coping, qualitative

ÖZ

OTİZM SPEKTRUM BOZUKLUĞUNA BAKIM VEREN EBEVEYNLER: İHTİYAÇ ANALİZİ, MODEL TESTİ VE MÜDAHALE ÇALIŞMASI

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Bu çalışmanın amacı otizm spektrum bozukluğu tanısına sahip çocukların bakım verenlerinin iyilik hallerini yordayan etmenleri incelemek ve bu bakım verenler için bir grup müdahale programı geliştirmektir. Bu tez birbiri ile ilişkili üç ayrı çalışmadan oluşmaktadır. Bu çalışmalar (1) otizm spektrum bozukluğu birincil bakım verenlerinin problemlerini belirleme, (2) birincil bakım verenlerin iyilik hallerini yordayan etmenleri Holahan ve Moos'un (2007) entegre başa çıkma modeli çerçevesinde ortaya çıkarma ve (3) otizm spektrum bozukluğu birincil bakım verenlerine yönelik bir grup müdahale programı geliştirmek ve uygulamaktır. Birinci çalışma otizm spektrum bozukluğu birincil bakım verenlerinin öznel deneyimlerini 6 katılımcı ile incelemiştir. Bu çalışmada belirlenen temalar yetersiz bilgi, duygular, sosyal destek ve değişim'dir. İkinci çalışma 72 katılımcı ile gerçekleşmiştir. Bakım verenlerin depresif semptom, olumlu duygulanım, olumsuz duygulanım, temel ihtiyaçların karşılanma ve yaşamsal faaliyetleri yerine getirme seviyelerinin yordayan etmenleri belirlemek üzere beş ayrı hiyerarşik regresyon analizi yapılmıştır. Üçüncü çalışma, birinci çalışmada elde edilen bulgular ışığında bir grup müdahale programı geliştirme ve uygulamayı kapsamaktadır. Bu çalışma 6 katılımcı ile gerçekleştirilmiş ve uygulanan müdahale programının sonunda otizm tanılı çocukların birincil bakım verenlerinde pozitif duygulanım ve iyilik hali göstergeleri (temel ihtiyaçların karşılanması ve yaşamsal faaliyetlerin yerine getirilmesi) puanlarının çalışma öncesi puanlarına göre anlamlı bir şekilde arttığı görülmüştür. Bu üç ayrı fakat ilişkili çalışmanın sonuçlarının olası açıklamaları tartışılmış, çıkarımları ve sınırlılıklarından bahsedilmiştir. Genel olarak bu tez otizm spektrum bozukluğu birincil bakım verenlerinin deneyimlerini ihtiyaç analizi, nitel ve nicel çalışmalarla incelemiş ve birincil bakım verenler için geliştirilebilecek müdahale programları ile ilgili önemli etmenlere ışık tutmuştur.

Anahtar Kelimeler. Birincil Bakıcı, Otizm Spektrum Bozukluğu, OSB, müdahale, uyum, başa çıkma, nitel

Dedicated to good people, songs and nature...

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CHAPTER 1

INTRODUCTION

While everyone needs care during infancy and childhood; people with chronic illnesses, disabilities, and developmental disorders need permanent or long-term caregivers and most of the time these caregivers are family members. Approximately there were 43.5 million unpaid caregivers in the US. in 2015 and while % 60 of them were female, % 85 of these caregivers were caring one of their relatives (Caregiving in the U.S., 2015). Since caregiving consumes time, money and resources of caregiver, it can be a great source of stress and burden. The emotions and cognitions emerging from caregiving experiences depend on various factors and the relations among these factors. The demographic characteristics of caregiver, social support perceived and coping strategies used by the caregiver, and the symptom severity of care-receiver both affect and affected by the cognitions, emotions, and behaviors of caregiver. Some of the characteristics of care-receiver's condition do also influence the burden of the caregiver; when the care-recipient has long-term physical conditions, memory problems, behavioral problems or developmental/intellectual disorder, caregivers generally report higher burden. Furthermore, the duration of caregiving also affects the perceived physical health; with the increase in the duration of caregiving, caregivers are less likely to report their health as very good or excellent (Caregiving in the U.S., 2015).

Like most of the children with neurodevelopmental disorders, children who are diagnosed with autism spectrum disorder need full-time caregiving in most of the cases (Ruiz-Robledillo & Moya-Albiol, 2015). With the increase in the prevalence rate of autism spectrum disorder, more and more children were diagnosed with this disorder, which also means increased number of autism spectrum disorder caregivers. According to Centers for Disease Control and Prevention, autism spectrum disorder occurs approximately one in every 68 births (2014). People with autism spectrum disorder show deficits in social communication and interaction as well as restricted and repetitive patterns of behavior, interests, or activities in varying degrees. Depending on how much caregiving needed by the person diagnosed with autism spectrum disorder, there are three levels of autism spectrum disorder according to DSM-V; level 1 “requiring support”, level 2 “requiring substantial support” and level 3 “requiring very substantial support” (DSM-V, 2013). As it can be understood from diagnostic criteria, most of the people with autism spectrum disorder –if not all- needs support in varying degrees.

In Turkey, children with autism spectrum disorder can receive education at the inclusive education, at special education classes, at autistic children education centers or at autistic children occupation education centers. The children with autism spectrum disorder should get health certificate from public hospitals in order to get education; and then Ministry of Education of Turkey covers the education expenses (Otizmli Bireylerin Hakları, 2013)

Since the well-being of caregivers depends on different variables, it is important to mention these variables and their impact on the well-being of caregivers. In this chapter of the thesis, general knowledge about caregiving and autism spectrum disorder will be provided. Furthermore, effects of caregivers' demographic variables, social support received or perceived by caregivers, coping strategies used by caregivers will also be discussed. This chapter ends with a summary of the literature on the well-being of caregivers of children with autism spectrum disorder; their levels of stress, depression, and anxiety, as well as their physical health and burden.

1.1. Caregiving

1.1.1. Demographic Factors

Demographic characteristics of caregivers sometimes play a significant role in the quality of life, stress, depressive and anxiety symptom levels of caregivers, and even on children's symptom severity. It has been found that family income is negatively correlated with the level of depression and stress of caregivers and severity of autism (Athari, Ghaedi, & Mohd Kosnin, 2013). Moreover, maternal age is negatively correlated with the level of anxiety (Falk, Norris, & Quinn, 2014; Barker et al., 2011). These results mean that as family income decreases, mothers caregiving their children with autism spectrum disorder report higher levels of depression and stress, and the children's disorder severity increases. It is important to mention the association between severity of autism spectrum disorder and family income. Because of the scarcity of money, parents cannot reach effective/appropriate education and treatment options for their children with autism spectrum disorder, which might explain the increase in the severity of autism. On the other hand, for fathers, although age was not correlated with anxiety, the level of stress was negatively correlated (Falk, Norris, & Quinn, 2014). Eventually, while both fathers and mothers reported increased levels of stress, mothers were found to be more stressful than fathers (Dabrowska & Pisula, 2010)

Longer caregiving duration may also affect the anxiety and depression levels of the caregivers of children with autism. It was found that after ten years of caregiving, anxiety levels of caregivers' significantly decreased but the level of their depressive symptoms was not significantly changed (Barker et al., 2011).

1.1.2. Social Support

As mentioned above, social support is a well-known protective factor for caregivers. Like other protective factors, with the increase of social support perceived by the caregiver, different components of well-being are positively affected. There is a positive correlation between social support and family adaptability, family functioning, and family quality of life. In other words, while social support increases, the family adaptability (Lin, Orsmond, Coster, & Cohn, 2011), family functioning (Manning, Wainwright, & Bennett, 2010), and family quality of life (Pozo, Sarriá, & Brioso, 2013) increase, as well. Moreover, Stuart and McGrew's study (2009) showed that the individual and family burden decreases when social support is increased. Likewise, both maternal and paternal depression and stress were negatively correlated with social support; but anxiety was negatively correlated with social support only in fathers of children with autism spectrum disorder (Falk, Norris, & Quinn, 2014).

1.1.3. Coping

Coping strategies used by the caregiver is another predictor of caregivers' well-being. Based on the study of Lazarus and Folkman (1984), coping strategies were generally grouped into two categories; namely problem-focused coping strategies that aim to solve the problem or doing something in order to change the source of stress, and emotion-focused coping strategies that aim to manage or reduce feelings related to the stressor. Most of the studies investigating coping strategies used this categorization. For instance, a study that compared U.S. and Taiwanese mothers suggested that increase in problem-focused coping means higher levels of family adaptability. On the other hand, less emotion-focused coping meant higher levels of family adaptability for U.S. mothers but not for Taiwanese mothers

(Lin, Orsmond, Coster, & Cohn, 2011). Likewise, mother caregivers who utilize more problem-focused coping than emotional focused coping strategies reported higher levels of well-being (Benson, 2010; Pozo, Sarriá, & Brioso, 2013), less perceived stress, and less perceived child behavioral problems as well as increased daily positive mood, lower depressive symptoms, and higher parental satisfaction. On the other hand, it was found that emotion-focused coping and disengaged coping, which corresponds closely to the category of emotion-focused coping (Benson, 2010), increased the stress level of caregivers (Dabrowska & Pisula, 2010). Disengaged coping did also indirectly affect the stress level of caregivers via children behavior problems. Relying more on disengaged coping led to higher perceived child behavior problems, which in turn, resulted in higher perceived stress level. In other words, caregivers who relied more on disengaged coping managed child's behavior problems less effectively (Lovell & Wetherell, 2015). Moreover, it was found that there is a significant adverse effect of disengagement/emotion-focused coping on the well-being of caregiver (Benson, 2010). Although most of the studies supported the claim that problem-focused coping strategies are negatively correlated with caregiver burden, stress and decreased well-being; there are some studies that could not verify these associations. For instance, according to Stuart and McGrew's (2009) study, although people who employ problem-focused coping strategies are expected to report decreased burden, this association has not been demonstrated. As it was mentioned above, although problem-focused coping generally has more advantages over emotion-focused coping; selection of coping strategies should be matched with adaptive tasks, and there are some exceptions that emotion-focused coping has more advantages over problem-focused coping due to characteristics of the stressful situation (Holahan & Moos, 2007). Likewise, it was theorized that problem-focused coping preferred in the case of high-appraised control and emotion-focused coping preferred in the case of low-appraised control (Folkman & Moskowitz, 2004). Therefore, it is important to distinguish controllable and uncontrollable parts of stress related to child's autism spectrum disorder and use proper coping strategies. Conway and Terry referred this relation between personal control and the situation as the goodness of fit (1992).

1.1.4. Well-being

Having a child diagnosed with autism spectrum disorder can affect parents in different aspects. While this diagnosis means giving up their dreams of their children, most of the caregivers cannot pursue their careers, as well (Zima, Kokot, & Rymaszewska, 2011). Moreover, individuals with autism spectrum disorder can be aggressive, impulsive or hyperactive or they may show unusual eating and sleeping habits, and have short attention (National Autism Association, 2014), all of which can make caregiving process emotionally, socially, and physically challenging.

When caregivers of children with autism spectrum disorder are compared with the caregivers of children with other neurodevelopmental disorders or with the caregivers of children who were typically developed, adverse impacts of autism spectrum disorder on caregiver well-being can easily be realized. Having a child with autism spectrum disorder is a greater source of burden for caregivers as compared to having a child with Down syndrome. (Zima, Kokot, & Rymaszewska, 2011; Eisenhower, Baker, & Blacher, 2005). Likewise comparing autism spectrum disorder caregivers to the general population, they possess higher levels of chronic stress (Ruiz-Robledillo & Moya-Albiol, 2015), depression (Manning, Wainwright, & Bennett, 2010) and anxiety (Dabrowska & Pisula, 2010), and poorer perceived general health (Bouma & Schweitzer, 1990; Hayes & Watson, 2012).

The severity of symptoms is another factor that may increase the caregiver burden and stress. It has been observed that the increase in the severity of symptoms of autism spectrum disorder and the behavioral problems may lead to higher levels of individual and family burden (Stuart & Mcgrew, 2009), higher levels of caregiver stress (Lecavalier, Leone, & Wiltz, 2006; Lovell, Moos, & Wetherell, 2013), and lower levels of family quality of life (Pozo, Sarriá, & Brioso, 2013). While most of the studies demonstrated that there is a positive correlation between child's behavior problems/symptoms and caregiver stress, Manning et al.'s (2010) study showed that while behavior problems predict higher stress levels, symptom severity is not correlated with caregiver stress level. In a similar vein, Huang and Chen's study (2014) showed that caregiver stress is highest when the child has mild to moderate behavior problems and autism spectrum disorder symptoms. This difference was explained by lower expectations of caregivers from their children with severe autism spectrum disorder. On the other hand, another study suggested that caregivers who use more problem-focused coping strategies report lower levels of stress due to the child's behavioral problems (Lovell & Wetherell, 2015). This finding suggested that it is not the children's behavioral problems and symptoms that cause stress but how caregiver handles the situation might be the actual source of stress. Although most of the studies indicated a positive correlation between caregiver stress and child's behavioral problems and symptom severity, there are some other studies that could not verify this association. According to Benson's (2010) study conducted with one hundred and thirteen caregivers of autism spectrum disorder, while the level of child problem behavior was not a significant predictor of maternal well-being, the heavy use of emotion-focused coping strategies might be problematic if the child with autism spectrum disorder display relatively less intense behavioral difficulties.

Depression is another probable outcome of the caregiving process. There are several studies demonstrating that the caregiver of a child with autism spectrum disorder can have higher levels of depression due to the child’s symptom severity (Athari, Ghaedi, & Mohd Kosnin, 2013), and aggressive behavior, as well as decreased social support and parental locus of control (Falk, Norris, & Quinn, 2014). Caregiver's depression does not only affect the well-being of caregiver but also of the care-receiver via the caregiver's depression. According to the study of Mazefsky et al. (2010), maternal depression and anxiety can explain child's comorbid depression and anxiety. Therefore, interventions aiming to decrease the caregiver depression may not only positively affect the caregiver well-being but also may reduce children's depression and anxiety levels.

1.2. Significance and Purpose of the Study

The present thesis aims to examine the predictors of caregiver depression, positive affect, negative affect and well-being of caregivers of children with autism spectrum disorder as well as to develop an intervention program specifically designed for these caregivers. This thesis is composed of three interrelated studies. The first study is designed to analyze the needs of caregivers of autism spectrum disorder. In this qualitative study, an interview targeting the caregivers was prepared to determine their needs. The second study aims to reveal predictors of caregiver depression, stress, and well-being by using an integrative coping model proposed by Holahan and Moos (2006). The last study of this thesis aims to develop and implement an intervention program based on the findings of qualitative phase of this dissertation and examine its effectiveness.

Although there are several interventions conducted with caregivers of different illnesses, disabilities, and disorders, as far as we know, this thesis is the first study that develops an intervention program based on the needs of caregivers of children with autism spectrum disorder in Turkey. Moreover, the assessment of caregiver depression, stress, and well-being predictors through the integrative coping model of Holahan and Moos (2006) may provide another pathway to understand which kind of interventions are needed for autism spectrum disorder caregivers.

CHAPTER 2

STUDY 1: QUALITATIVE ASSESSMENT OF ADAPTATION TO CAREGIVING FOR CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

2.1.INTRODUCTION

Although there are not many qualitative studies conducted with the caregivers of children with Autism Spectrum Disorder, qualitative studies provide important and detailed information about the caregiving process and its related cognitions, emotions and behaviors.

The study of Myers et al. (Myers, Mackintosh, Goin-Kochel, 2009) identified five different clusters. The first one was stress, which is the most common theme of the study. Over the 70 % of the caregivers used statements related to stress. The second cluster was the child's behaviors and the demands of the child's therapy and care. This cluster had four negative and two positive themes, namely (1) difficulty in dealing with child's behavior problems, (2) time demanded for care and therapies, (3) sleep problems, exhaustion, (4) struggles with schools and services, (5) new understanding regarding the world of disabilities, and (6) glad for child's autism, uniqueness, would not change it (child's autism diagnosis) if we could. The third cluster was the impact on parents' personal well-being, which has three negative and five positive themes, namely (1) marital or couple strain, (2) difficult emotions: grief, depression, guilt, blame, (3) mother's and/or father's career/employment affected, (4) enriched our lives, a blessing, love for this child, (5) positive emotions: taught us compassion, tolerance, patience, joy, (6) learned to appreciate the little things, slow down, (7) spiritual life enriched, and (8) marriage enriched. The fourth cluster was work life and marital relationship. In this cluster, there were four negative and two positive themes, and the positive themes were the counterparts of the negative ones: (1) effects on siblings, (2) financial strain, (3) the feeling that autism became the center of their lives, and (4) strained relations with extended family members were the negative themes; and (1) positive family adjustment and (2) positive impact on sibling were the positive ones. The last cluster was social isolation, the themes of which were (1) restrictions on where we can go and what we can do, (2) lost friends, no social life, and (3) bad treatment by strangers

Another study conducted with 22 mothers of children with autism spectrum disorder depicted similar results. In this study, researchers asked open-ended questions about the impact of diagnosis on caregiver and family, society's reactions, factors that support caregiver, and necessary qualities of caregivers of children with autism spectrum disorder. In this study most of the caregivers emphasized the negative aspect of the autism spectrum disorder diagnosis as shattered dreams, major negative changes in family life, child's rejection by the father, denial of the diagnosis, depression, neglecting the other child(ren), and disagreements between spouses. Moreover, there were some negative emotions like fear of changes, unhappiness, despair, and helplessness emphasized by these mothers. Only small portion of these mothers identified positive aspects of this diagnosis as increased family unity and a change in a constructive manner. Furthermore, when society's reaction was asked, all mothers emphasized the tendency of individuals to marginalize the child with autism spectrum disorder and his/her family as well as lack of understanding from society. Supporting factors arose from this questionnaire were the importance of hope, trust in God, support from family, and support by specialists. Mothers indicated that a caregiver of a child with autism spectrum disorder should have or should develop optimism, commitment, understanding to overcome the critical moments, patience, and perseverance in making efforts to help their child (Oprea & Stan, 2012).

The effect of caregiving on employment was examined by a qualitative study carried out by McCabe (2010). According to results of this study, for mothers in China, caregiving meant sacrificing their own lives for their children with autism spectrum disorder. This sacrifice included their career and their identity apart from being a mother. Moreover, because of lack of educational services in China, mothers became their children's own teacher. Interestingly, it was found that these mothers hoped that their children can enter school and typically develop like other children who did not have any disorder. Since the symptoms of autism spectrum disorder frequently appears throughout children's life, these beliefs and hopes can be a source of disappointment as well as higher levels of stress and depression for these mothers who indicated the importance of education about autism spectrum disorder for the caregivers and help them to cope with the consequences of the disorder.

The qualitative study conducted with 16 Turkish mothers of children with autism spectrum disorder showed that mothers appraise this disorder as uncontrollable, unchangeable, and enduring (Aslanlı, Cihan, & Altın, 2014). Another qualitative study conducted with 6 mothers of older adolescents diagnosed with autism spectrum disorder (Mason, 2012) showed that while isolation, coping with their child's challenging behaviors, and frustration with the establishment increase the stress levels of the caregivers, professional behavior or support teams, support from others, and church or spiritual connection decrease their stress levels.

In the study of Truett (2012) three themes emerged; namely, service issues, awareness of autism, and emotional continuum. According to service issues theme, parents complained about financial concerns, amount of services, lack of information, and waiting for services. In the awareness of autism theme, the main concerns of caregivers were lack of knowledge or awareness of medical, educational professionals, family members, and the general population. The last theme, emotional continuum, contained emotions of caregivers, which were negative most of the time.

In the light of the literature mentioned above, the aim of the present study was to define the factors associated with caregiving from the perspective of caregivers and to develop an intervention program for caregivers of children with autism spectrum disorder based on these factors. In order to define these factors associated with caregiving, an interview comprising the subjects listed below was conducted:

1- The emotions of caregivers of children with autism spectrum disorder,
2- Caregivers' opinions about their knowledge related to autism spectrum disorder,
3- Caregivers' experiences about diagnosis and caregiving processes,
4- Coping mechanisms that are used by caregivers,
5- Perceived and received social support
6- Caregivers' opinions about their child's future
7-

2.2. Method

2.2.1 Participants

Six caregivers of a child with autism spectrum disorder participated in the need assessment study. Four of them were mothers of these children and two of them were fathers. The age of the participants ranged between 33 and 46 and the mean age was 40.67 (*SD* = 4.41). All of the participants were married and they identified themselves as a member of middle-income group. Five of the participants (83 %) were university graduates and 1 of the participants was high school graduates (17 %).

All the participants' children were diagnosed with autism spectrum disorder. The time passed since their diagnosis ranged between 2-8 years with a mean of 4.83 years. The age of the children ranged between 4 years and 13 years (*M* = 7.5; *SD* = 3.94). One of the children (17 %) whose mother is a participant of Study 1 was female and 5 of the children (83 %) was male.

2.2.2 Measures

2.2.2.1. Interview Question Form

The interview questionnaire form consisted of nine questions. The aim of the interview questions was to assess the problems of the caregivers. The main content of the questions was about the diagnosis process and the emotions related to this diagnosis, the main changes occurred in their life and how they cope with these changes. The answers of the caregivers were evaluated with thematic analysis (see Appendix A).

2.2.2.2. Procedure

Ethical approval was obtained from Middle East Technical University Review Board and participants were reached from a special education and rehabilitation center in Eskişehir, Turkey.

After selecting the participants, they were informed about the aim and the rationale of the study. Following this, audio recording was started with the consent of the participants. Two of the participants did not allow audio recording; thus, the interviewer transcribed their answers during the interview.

The interviews were started with the questions about how the participants decided to see a doctor for their child, what they experienced during this process, how they felt during the process, and about the changes occurred in their life during this process. After these questions, interviews were continued with the questions about participants' knowledge about autism spectrum disorder, their opinions about the education their child received, the difficulties they encountered after the diagnosis, and how they coped with these difficulties. The interviews ended with questions on the self-perception of caregivers regarding their weak and strong sides, and on their expectations about future. The interviews were conducted at the psychologist's office in the special education and rehabilitation center, and lasted approximately for 25 minutes.

2.2.2.3. Data Analysis

Throughout the qualitative phase of this study, the steps suggested by Braun and Clarke (2006) were utilized to conduct a thematic analysis. During the initial phase of the analysis, audio recording of the interviews have been transcribed and meticulously examined to generate the initial codes. At this stage of data analysis, potential themes and recurrent patterns that have been identified in the transcripts were coded. At the next stage, initial codes that were generated at the previous stage were clustered to identify themes. Having identified some themes, these themes were reviewed to determine whether there are sufficient data to support the identified themes, whether the themes are too diverse, and whether different themes could be combined into one theme. At the last step of thematic analysis, each theme was further defined and named. The result section of this chapter presents the themes with representative quotations and frequencies.

2.3. Results: Themes

There were four themes emerged from the need assessment study of this thesis. The first theme was "insufficient knowledge", the second theme was "emotion", third one was "social support", and the fourth theme was "changes". The numbers in parentheses represent the number of participants who expressed statements related to the respective theme.

2.3.1. Insufficient Knowledge

All of the participants reported insufficient knowledge about autism spectrum disorder (*n* = 6).

“We don’t have sufficient knowledge, because there are very few people with the same characteristics around us.” (Yetersiz bilgiye sahibiz. Çünkü çevremizde aynı özellikleri gösteren kişi sayısı çok az)

“I don’t think that I have sufficient knowledge about this disorder. I think we still lack some knowledge.” (Bu bozuklukla ilgili yeterli bilgiye sahip olduğumu düşünmüyorum, hala eksiklerimiz olduğunu düşünüyorum...)

Moreover, most of them (*n* = 4) expressed that when their child received this diagnosis, the doctors and counseling research center workers did not properly inform them about autism spectrum disorder.

"When I went to see a doctor, s/he did not explain it (autism spectrum disorder) to me. When I went to counseling center, they took my documents and handed me the reports regarding the education I was about to receive, but nobody informed me about it." (Bir doktora gittiğimde bana bunu (otizm spektrum bozukluğu) anlatmadı. Rehberliğe gittiğimde evraklarımı aldı, eğitim göreceğime dair raporları elime teslim ettiler, bununla ilgili bilgi veren yine olmadı.)

2.3.2. Emotion

When participants’ emotions regarding their child’s autism spectrum disorder were asked, all of them expressed negative emotions. Sadness was the most commonly expressed emotion by the participants (*n* = 6). Participants reported that their sadness peaked short after the diagnosis. Although they also articulated that their sadness declined in time, the majority of them (*n* = 5) expressed that they still feel sad.

“ We were sad, but we knew that this thing wouldn’t be resolved by being sad.” (Üzüldük, ama üzülmeyle bu işin çözülmeyeceğini biliyorduk.)

“Oh at that time we felt so sad that we didn’t want to believe it at first.” (Ha biz çok üzüldük mesela o zaman da, şöyle önce inanmak istemedik.)

“I felt so sad, I cried.” (Çok üzüldüm, ağladım.)

“My whole world, as a matter of course, got shaken” (Dünyam yıkıldı doğal olarak)

“When I first heard about this (that his/her child has autism spectrum disorder) and learned that there is such a thing, I felt very sad,. That process, until the diagnosis… I was also feeling sad, when I first came here (Special Education and Rehabilitation Center). Diagnosis has been given, and I am coming here, I was spending my entire time crying in here. I can’t tell why, perhaps I don’t think it was befitting, maybe because of sadness, or seeing other people around me, I don’t know. I spent my entire time crying.” (çok üzüldüm ben. Yani, ilk bunları (çocuğunun otizm spektrum bozukluğuna sahip olduğunu) duyduğumda da, böyle bir şeyin olduğunu duyduğumda da çok üzüldüm. O süreç, teşhis konulana kadar. Ben buraya (özel eğitim ve rehabilitasyon merkezi) ilk geldiğimde de üzülüyordum. Teşhis kondu, buraya geliyorum, hep ağlamakla geçiyordu benim zamanım burada. Sebebini bilemiyorum, belki yakıştıramıyorum, belki üzülüyorum, belki etrafımdakileri görüyorum, bilemiyorum. Hep ağlamakla geçiyordu).

Anxiety is another emotion that was frequently expressed by the participants (*n* = 5). Participants' anxiety was generally about their child's future. Participants were anxious about their child's school life, whether they can learn to read, get married, get a job and earn money, and what will happen to them if and when the parents pass away.

"I get worried, I get worried a lot about everything. So, our child is four and a half years old, and we are thinking about whether s/he can marry or not." (Kaygılanıyorum, çok kaygılanıyorum hem de her konuda. Yani öyle bir şey ki çocuğumuz dört buçuk yaşında, evlenebilecek mi diye düşünüyorsunuz.)

"S/he will be alone. Will s/he earn money? How s/he is going to make her/his living? Fear, anxiety, sadness... all of it." (Yalnız kalacak, maaşı olacak mı, nasıl geçinecek biz olmasak? Korku, kaygı, üzüntü...hepsi)

"Of course, my anxiety increases as my son gets older. We struggle with endless questions like "How is it going to be?, Will he learn how to read? Is he going to have a job?, Will he fall in love?"" (Kaygılarım oğlum büyüdükçe artıyor tabi ki. Nasıl olacak okuma öğrenecek mi? Bir işi olacak mı? Aşık olacak mı? gibi bitmez sorularla mücadele ediyoruz)

"Our worry and fears are regarding his/her future. What will happen, if we die?" (Geleceği açısından endişemiz, korkumuz. Biz ölürsek nolur?)

"I've come across an article the other day. It says: "Every parent hopes to die before their children pass away. Only parents who have children with disabilities want that their children will die before them." We feel exactly the same. We have to live longer than them so that we can support them." (Geçen gün bir yazı vardı. Diyor ki: 'Her anne baba evladından önce ölmeyi temenni eder. Sadece özürlü çocuğu olanlar evladının önce ölmesini ister.' diyor. Tam olarak öyleyiz. Yani onlardan uzun yaşamak zorundayız ki onlara destek verebilelim.)

Two of the mothers and one of the fathers (*n* = 3) who participated in this interview, expressed increased anger towards other people including their own children with autism spectrum disorder.

“I usually get easily angry and react.” (çabuk sinirlenip tepki verebiliyorum.)

Although it is not a physical violence, we hurt each other as well as our children with verbal violence. (fiziki olmasa bile sözlü-şiddetle hem birbirimizi hem çocukları etkiliyoruz.)

“I eventually say, “I need to go somewhere”, “there must be someone to leave my kid with.” With that anger, I spill out all that anger to his father.” (Artık diyorum ki “bir yere gitmem gerekiyor”, “çocuğu bırakacağım bir insan olmak durumunda”. Artık o sinirle, bütün sinirimi babasına kusuyorum.)

On the other hand, there was only one statement expressing positive emotions, which was articulated by a father of a child with autism spectrum disorder.

“We are happy that we have a kid like him/her. We’ve learned the preciousness of life with him/her. We love him/her very much.” (Onun gibi bir çocuğumuz olduğu için seviniyoruz. Onunla hayatın kıymetini öğrendik. Onu çok seviyoruz.)

2.3.3. Social Support

Participants frequently expressed lack of social support from their families and friends (*n* = 5). Most of them mentioned that only their spouses support and help them with their child's caregiving (caregiving of their child with autism.)

"We haven't received sufficient support from our family members. We'd like them to help us but since it didn't happen to them, and since they don't have any information about it, they're not aware of the situation." (Aile fertlerinden yeterli desteği görmedik. Yardımcı olmalarını isterdik ama başlarına gelmediği ve bilgi sahibi olmadıklarından bu olayın farkında değiller!)

"They're already not properly aware of the situation. They still cannot accept it. Therefore, we don't receive any support from them. They rather have a judgmental and questioning attitude toward our behaviors as parents of this type of children. They think we are the reason of this situation. We don't receive any family support." (Zaten durumun farkındalıkları zayıf.... Halen onlarda kabul edememezlik var. Dolayısıyla onlardan bir destek göremiyoruz. Daha çok böyle çocuklarla ilgili davranışlarımızı, bizim ebeveyn davranışlarımızı sorgular tavırları var. Bizden kaynaklandığı gibi düşüncelere sahipler. Aile desteği alamıyoruz.)

"My family stayed with us for one and a half month, I couldn't make them stay just for one more day. They couldn't take it anymore. They tried it but whenever I invite them again, they do anything to avoid it." (Benim ailem bir buçuk ay kaldı, 1 gün fazla tutamadım onları. Dayanamadılar. Gayret gösterdiler ama şimdi tekrar davet ettiğimde gelmemek için her şeyi yapıyorlar.)

"We don't receive much support from family members, I can even say that we receive almost no support whatsoever." (Aile fertlerinden destek çok fazla görmüyoruz, hatta hemen hemen hiç görmüyoruz sayılır.)

"We have usually left alone regarding his/her caregiving. Our families were not with us. Sometimes I think that I can't keep up with it." (Bakımı ile ilgili genelde yalnız olduk. Ailelerimiz yanımızda olmadı. Bazen yetişemediğimi düşünüyorum.)

One of the mothers who was a participant in the interview expressed that there have been adequate support from her family but not from her husband or her husband's family.

"For instance, my parents come over during the winter, they stay with me for a while, and I go to their place during summer and stay quite a while. My parents were staying with me, and when they're around, yes, I'm really at ease." (Annemler geliyorlar mesela kışın, belli bir dönem benim yanımda kalıyorlar, yazın ben gidiyordum epeyce bir süre kalıyordum. Annemler yanımda kalıyordu, onlar yanımda olduğu zaman, evet, çok rahatım.)

"There is no one in my family with judgmental attitudes towards us. It is such that there is a positive attitude privileging my daughter besides others (grandchildren). (Ailemde bizi yadırgayan, yan gözle bakan, ya da "aman aman o bir dursun" diyen biri yok. Hatta kızım bir yana, diğerleri (torunlar) bir yana, o şekilde.)

"But we haven't had a contact with my husband's family for a long time. When we ask their opinion, they supposedly have nothing bad to say. They just don't want to take care of my daughter." (.... Ama eşim tarafıyla zaten çok uzun zamandır görüşmüyorduk, onların bakış açısını sorarsak, sözde olarak onlar da bir şey demiyorlar. Sadece, (kızımı) almak istemiyor, bakmak istemiyorlar…)

To her husband: “OK, you’re working, but I get extremely bored. You don’t take care of us; there is no one around you to make you take care of us. My family isn’t here. There is a child in need.” ((Eşine) Tamam, sen çalışıyorsun, adın var çalışıyorsun, ama benim de ruhum sıkılıyor artık. Sen bizle ilgilenmiyorsun, çevrende kimse yok bizimle ilgilenmeni sağlayacak. Benim ailem yok burada. Zor da bir çocuk var.)

2.3.4. Changes

Another theme emerged from interviews was the changes after autism spectrum disorder diagnosis (*n* = 5). Participants expressed that their lives have dramatically changed after their child’s diagnosis in terms of social activities, behaviors, and daily life.

“You constantly feel that you have to explain yourself to others and apologize from them. When with other people, one feels him/herself as looser. This then leads to social withdrawal and results in introversion.” (Sürekli olarak kendinizi açıklama ve özür dileme konumunda hissediyorsunuz. Etrafa karşı ezik bir tavır halinde oluyor insan. Bu da daha az gitme daha az gelme ile devam edip içeriye doğru kapanmayla sonuçlanıyor.)

“It (our life) has changed a lot. It got restrained. It changed socially. We withdrew ourselves from social activities.” (Hayatımız çok değişti. Hayatımız kısıtlandı, sosyal anlamda değişti. Sosyal aktivitelerden kendimizi çektik.)

“For example, there was a funeral for a friend of mine. I didn’t want to go there. I worried about how they are going to treat my kid, whether someone will say anything and I will inappropriately react to them." (Mesela arkadaşımın cenazesi vardı. Oraya gitmek istemedim. Çocuğa nasıl davranacaklar, birisi bir şey söyler, ben ters tepki gösteririm.)

"Everything have changed for me, everything. I couldn't easily carry out my daily activities. My daughter started walking. When children first start walking, usually mothers easily go out using strollers, but my daughter did't even let me do that. She started to jump off the stroller immediately after she learned to walk." (Benim için her şey değişti, her şey. Ben rahat rahat işimi gücümü yapamıyorum. Kızım ayaklandı, ilk ayaklandığında, normalde anneler bebek arabalarıyla rahat rahat dışarı çıkarlar, ama kızım onu bile yaptırmadı bana. Ayaklanıp bacağını atma hareketini öğrendiği anda arabadan atlamaya başladı.)

2.4. Discussion

The aim of the Study 1 was to identify the subjective experiences of caregivers of children with autism spectrum disorder and the problems of these caregivers. In order to identify these subjective experiences and problems, a thematic analysis conducted within the frame of Braun and Clarke's study (2006). There were four themes emerged from this study, namely, (1) insufficient knowledge, (2) emotions, (3) social support, and (4) changes.

2.4.1. Insufficient Knowledge

Regardless of the diagnosis time, all of the caregivers expressed a belief of insufficient knowledge about autism spectrum disorder. This result is congruent with the results of Truett's study (2012), in which one of the three themes was "awareness of autism theme". According to "awareness of autism theme" the main concerns of caregivers were the lack of knowledge or awareness of medical or educational professionals, family members, and the general population. Likewise, in the first study of this thesis, caregivers expressed that they were not sufficiently informed about their child's diagnosis and they would like to know better what autism spectrum disorder is. The study of Patra et al. (2015) revealed that at the end of a psychoeducational intervention program that aimed to give information to caregivers about autism spectrum disorder, the stress level of caregivers was significantly decreased, which was negatively correlated with knowledge about autism spectrum disorder. Increased knowledge about autism spectrum disorder can help caregivers in terms of developing realistic goals and decrease uncertainty about their children's autism spectrum disorder. Therefore, this theme constituted an important component of the caregiver intervention program (Study 3).

2.4.2. Emotions

Emotions was the second theme emerged from Study 1 of this thesis. All of the participants of Study 1 expressed sadness due to their child's autism spectrum disorder diagnosis. Sadness, which is usually associated with the appraisal of permanent loss (Bonanno, Goorin, & Coifman, 2008), can be a result of their children's diagnosis as well as their restricted lives and shattered dreams.

Besides sadness, anxiety was the most frequent emotion expressed by caregivers participated in Study 1. According to DSM-V (2013), anxiety is the anticipation of future threat. Parallel to this definition, participant caregivers' anxiety was usually about their child's future. Caregivers were anxious about their children's future, especially about the things that will happen to them when they pass away.

Anger is another emotion that was expressed by half of the participants. Anger, which is associated with many psychological disorders, is regarded as a secondary emotion or symptom of a psychological disorder. Likewise, in a study conducted with dementia caregivers, increased scores in anger and lower scores in cognitive reappraisal were significantly associated with psychological disorders (Romero-Moreno, Márquez-González, Losada, & López, 2011). The participants of qualitative phase of this thesis expressed increased anger towards other people including their own children with autism spectrum disorder.

Positive emotions of caregivers regarding to their child's autism spectrum disorder diagnosis were revealed by some studies. Participants of the study of Myers et al. expressed their gladness for their child's autism and uniqueness. Moreover, they mentioned that their lives were enriched, their children's diagnosis taught them compassion, tolerance, patience, joy and they learned to appreciate little things (Myers, Mackintosh, & Goin-Kochel, 2009). Furthermore, increased family adjustment was expressed by some of the caregivers. (Myers, Mackintosh, & Goin-Kochel, 2009; Oprea, Stan, 2012). In Study 1 of this thesis, only one of the participants expressed positive emotions regarding to their child's autism spectrum disorder diagnosis. They emphasized that they learned the preciousness of life with their child.

Since Turkey is a collectivistic culture (Hofstede, 1980), in which people share fewer emotions (Singh-Manoux & Finkenauer, 2001), the lack of positive emotions expressed by participants may be due to the cultural charcteristics of Turkey. Moreover, anxieties expressed by the participants usually focused on their child's future. This can be interpreted as resulting from economic distress and insufficient social policies about autism spectrum disorder.

2.4.3. Social Support

Social support was the third theme emerged from the interviews. Although family adaptability (Lin, Orsmond, Coster, & Cohn, 2011), family functioning (Manning, Wainwright, & Bennett, 2010), and family quality of life increase (Pozo, Sarriá, & Brioso, 2013), and caregiver burden and depression level (Stuart & McGrew, 2009) decrease with the increase of social support; most of the participants expressed lack of social support received from their families or friends. Only one of the participants mentioned adequate support from her family. According to this participant, adequate social support helped her to satisfy her basic needs, such as getting enough sleep and eating healthy.

Autism is barely recognized in Turkey. According to the study of Tohum Autism Foundation ("Türkiye'de Her 10 Kişiden 7'si Otizmi Duymamış!", 2016), only 27 % of the population have heard the word "autism" before, and 93 % of this group did not know any symptoms of autism spectrum disorder. Therefore, it is highly possible that people may consider caregivers as an inadequate parent or the children as being spoiled rather than a child with autism spectrum disorder. This discrimination might be increased for children whose symptoms are mild since sometimes symptoms of autism are not easily recognizable. Therefore, lack of social support might be a result of this unawareness.

2.4.4.Change

All of the participants expressed significant changes in their life after the autism spectrum disorder diagnosis given to their child. Consistent with the study of Oprea and Stan (2012), these changes were generally in a negative manner. Similar to the findings documented in the relevant literature (e.g., Myers, Mackintosh, & Goin-Kochel, 2009), caregivers expressed restrictions in daily activities, as well as limited or no social life. Furthermore, according to participants, their style of communication with other people was changed after the diagnosis. Isolation from other individuals is a noticeable issue for the caregivers of children with autism spectrum disorder, which is more likely than non-caregivers to report social isolation (Glozman 2004,).

Again this theme should not be appraised apart from social and political elements. None of the participant caregivers were receiving economic support from government and on average these children were getting 12 hours of education per month (Heğci & Kırşehirli 2007). Therefore, one of the parents should spent almost all of his/her time with the child with autism spectrum disorder and the other parent should work. On the other hand, as described above, Turkish people are almost unaware of what autism spectrum disorder is. Therefore, parents cannot get sufficient social support, even though they would like to receive such support.

2.4.5. Implications for the Intervention

The aim of the Study 1 of this thesis was to assess problems of caregivers of children with autism spectrum disorder and design an intervention program pursuant to these problems. According to themes emerged from the thematic analysis conducted with the steps suggested by Braun and Clarke (2006), psychoeducation about autism spectrum disorder can help caregivers, since all of the participants expressed misbeliefs or insufficient information on autism spectrum disorder. Moreover, supporting caregivers in terms of expressing, sharing and coping with their negative emotions could help them. Therefore, caregiver intervention programs can be designed to help caregivers in dealing with their sadness, anxiety, and anger. Since most of the participants expressed insufficient social support, it became necessary to include "social support" to caregiver intervention program. They could be educated about importance of the social support, how to ask for social support and how to accept it. Lastly, almost all of the participants of Study 1 (n = 5) expressed that their life was changed in a negative manner. Thus, cognitive reframing changes can help them to increase their positive emotions. Moreover, situation-specific coping strategies might increase their adaptation as well as their positive affect. Finally, it can be necessary to express the importance of "acceptance" if the situation is not changeable.

In the light of information gathered in Study 1, the 7-week intervention program was designed and practiced with the caregivers of children with autism spectrum disorder. More information about this intervention program and the results of this intervention program was discussed in the Study 3 part of this thesis.

2.4.6. Limitations

Although there are several strengths of the Study 1, it is important to note its limitations as well. The first limitation of this study is its generalizability. The Study 1 of this thesis was conducted with only six participants. Moreover, all of the participants had high school or higher education and all of them appraised themselves as a part of middle SES. Therefore, the results of this qualitative study should be examined carefully.

The interview and thematic analysis were conducted by the same researcher, which brings about the subjectivity of researcher into consideration. This means that although the themes emerged from Study 1 of this thesis were consistent with the literature described above, objectivity can be another limitation of this study.

CHAPTER 3

STUDY 2: PREDICTORS OF CAREGIVER DEPRESSION, POSITIVE AFFECT, NEGATIVE AFFECT AND WELL-BEING AMONG THE CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

3.1 Introduction: The Model: Holahan & Moos Coping Model

The present study uses Holahan and Moos' (2007) integrative coping model as a theoretical framework. Diverse models of coping processes and resources, crisis theory, and biopsychosocial orientation have shaped this coping model.

Crisis theory (Caplan, 1964) focuses on how major life crises handled by individuals. According to crisis theory, individuals' reaction to chronic illness or disability affects the community and family; and in the first few days of the onset of a crisis, psychological first aid opportunities exist for family and community. After the first few days, with the reestablished coping, the crisis is resolved, and equilibrium will eventually occur whether for good or ill. This resolution has a significant effect on the overall health of neighborhoods, communities, and society (Slaikeu, 1984).

The biopsychosocial orientation to health care integrates psychosomatic orientation, which focuses on environmental and personal factors on the onset and progression of chronic disorders, and behavioral medicine that emphasize the role of the individual in managing and controlling the consequences of chronic illness or disability (Holahan, Moos, 2007).

At the "coping resources and processes" component of the integrative coping model of Holahan and Moos (2007), coping was classified into four groups as the following; cognitive approach coping, which includes search for meaning and cognitive reappraisal; behavioral approach coping, which includes taking problem-solving action and seeking guidance and support; cognitive avoidance coping, which covers cognitive avoidance or denial, and acceptance or resignation; and behavioral avoidance coping, which includes seeking alternative rewards and emotional discharge.

According to the model proposed by Holahan and Moos (2007), selection of coping skills is associated with health-related factors, personal resources, the social and physical context, cognitive appraisal, and adaptive tasks. Personal resources (Panel I), health-related factors (Panel II), and the social and physical context (Panel III) affect how the health-related condition is appraised (Panel IV) and how adaptive tasks are formulated (Panel V). Selection of coping skills (Panel VI) are determined by these factors, and these selected coping skills mediate the influences in Panels I through V and health-related outcomes (Panel VII).

Panel I, which is personal resources, compromises intellectual ability, ego strength, self-confidence, demographic characteristics like age, gender education, as well as personality characteristics, such as extroversion, optimism, internal control, and broad cognitive and problem-solving styles.

Panel II, which is health-related factors, includes rapidity of onset and progression of a condition, the stage and severity of illness, and the type of disability.

Panel III is the social and physical context. This panel includes social relationships and social support as social context. Moreover the physical features of a home and workplace like the ease of access to a physical setting are the physical context for this panel.

Panel IV, which is the cognitive appraisal, includes how the problem is appraised; whether as a challenge or threat, whether it is changeable or controllable.

Panel V, which is adaptive tasks, comprises of seven adaptive tasks;

namely managing symptoms, managing treatment, forming relationships with health-care providers, managing emotions, maintaining a positive self-image, relating to family members and friends, and preparing for an uncertain future. In order to analyze adaptive tasks of caregivers of children with Autism Spectrum Disorder, Caregiver Adaptation Scale for Autism (CASA) was developed by the present researcher, and these tasks are discussed in more detail in the method and result section of this chapter.

Panel VI, which is coping skills, consists of eight coping skills; namely, logical analysis and the search for meaning, positive reappraisal, seeking guidance and support, cognitive avoidance or denial, taking problem-solving action, acceptance, and resignation, seeking alternative rewards, and emotional discharge.

Health-related outcomes, which are related to Panel VII, like depression, stress, well-being, illness, disorder symptoms, and adherence are mediated by coping style. Although action focused approaches to coping strategies are generally associated with positive health-related outcomes, there are some exceptions where the avoidance coping strategies are more effective; and coping choices must be analyzed according to task requirements of the specific health crisis (Holahan & Moos, 2007). For instance, at the early stages of a traumatic event, denial may help the individual to regulate his/her mood (Goldbeck, 1997 retrieved from Holahan & Moos, 2007).

The study of de Vries (2012), which was used the adaptive tasks model of Moos and Holahan, proposed that maintaining a positive self-image, relating to family members and friends, managing treatment and managing emotions was the most influential ones for Dutch adolescents with chronic illness and disability.

Another study conducted with cystic fibrosis patients (Findler, Shalev & Barak, 2014), was also used Holahan and Moos model as a theoretical framework. In this study psychosocial adaptation of cystic fibrosis patient were examined. The result of this study proposed that psychosocial adaptation was significantly associated with gender, symptom severity and forming relationships with health-care providers.

In this thesis, the integrative coping model of Holahan and Moos (2007) was used as a theoretical framework for Study 2. Thus, based on the literature mentioned above, the aim of the second study of the present thesis was to test adaptive task and coping model of Holahan and Moos (2007). In more detail the aims of the present study were:

1. To examine the differences among the levels of demographic variables in terms of depression, positive and negative affect, and well-being in caregivers of children with autism spectrum disorder.

2. To examine the associations among demographic factors, self-efficacy, social support, adaptation to caregiving, coping strategies, depression, positive and negative affect, and well-being in caregivers of children with autism spectrum disorder.

Therefore, the hypotheses of the study were:

1. Perceived social support of caregivers will be
    a. positively associated with positive affect
    b. positively associated with well-being
    c. negatively associated with negative affect
    d. negatively associated with depression of caregivers.

2. Problem-focused coping strategies will be
    a. positively associated with positive affect
    b. positively associated with well-being

    c. negatively associated with negative affect
    d. negatively associated with depression of caregivers.

3. Emotion-focused coping strategies will be
    a. positively associated with depression
    b. positively associated with negative affect
    c. negatively associated with positive affect
    d. negatively associated with well-being of caregivers.

4. Adaptation to caregiving will be
    a. positively associated with positive affect
    b. positively associated with well-being
    c. negatively associated with negative affect
    d. negatively associated with depression of caregivers.

5. General self-efficacy will be
    a. positively associated with positive affect
    b. positively associated with well-being
    c. negatively associated with negative affect
    d. negatively associated with depression of caregivers.

3.2 Method

3.2.1. Participants

There were 72 participants in the Study 2 of this thesis. Fifty-nine of them were mothers of a child (81.9 %) and 13 of them were fathers (18.1 %). The ages of the participants ranged between 29 and 59 (*M* = 39.75, *SD* = 6.63). Seven of the participants (9.7 %) had no education or they were graduates of either primary school or middle school. Fifteen of the participants (20.8 %) had high school education and 50 of the participants (69.4 %) had a university or higher degree. Sixty of the participants (83.3 %) were married and 12 of them (16.7 %) were divorced, widowed or single. Regarding perceived socioeconomic status (SES), 9 of the participants (12.5 %) reported that they had a low SES, 56 of the participants (77.8 %) reported that they had a middle SES, and 7 of the participants (9.7 %) reported that they had a high SES. The majority (*n* = 48) of the participants reported that they had more than one child (66.7 %) and 24 of them (33.3 %) reported that they have only one child who has autism spectrum disorder. While 42 of the caregivers (58.3 %) reported that they received support in caregiving, 30 of them (41.7 %) reported that they did not receive any support. Moreover, caregiving duration ranged between 3 months and 264 months (*M* = 82, *SD* = 68.11).

Considering physical and mental health of the caregivers, while only 11 of them (15.3 %) reported as being diagnosed with a physical illness, 13 of them (18.1 %) reported that they have a physiological disorder diagnosis.

Table 3.2.1.*Demographic Characteristics of the Sample*

Variables	*N*	%	*M*	*SD*
Gender				
Female	59	81.9		
Male	13	18.1		
Age			39.75	6.63
Education				
Lower than High School	7	9.7		
High School	15	20.8		
Higher than High School	50	69.4		
Marital Status				
Married	60	83.3		
Single	12	16.7		

Table 3.2.1. *(Continued)*

Variables	*N*	%	*M*	*SD*
Number of Children				
One	24	33.3		
More than one	48	66.7		
Perceived SES				
Low	9	12.5		
Middle	56	77.8		
High	7	9.7		
Caregiving Duration			82.02	68.11
Physical Illness				
Yes	11	15.3		
No	61	84.7		
Psychological Disorder				
Yes	13	18.1		
No	59	81.9		
Support for Caregiving				
Yes	42	58.3		
No	30	41.7		

3.2.2. Measures

3.2.2.1. Demographic Information Form

The demographic information form is prepared for caregivers of children with autism spectrum disorder. The form includes general demographic questions regarding gender, education, age, income, marital status, physical illness and psychological health status of caregivers as well as the date of autism diagnosis, other people providing care for their child, and the number of children they have (including their child with autism spectrum disorder) (See Appendix B).

3.2.2.2. Beck Depression Inventory (BDI)

BDI (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) was used to measure the severity of caregivers' depression in terms of cognitive, behavioral, affective, and somatic components of depression. There are 21 multiple-choice questions in BDI, and the scores obtained from each item ranges between 0 and 3. Higher overall score from BDI (of 63) reflects a greater level of depression. BDI was adapted to Turkish by Hisli (1988), and test-retest reliability of the BDI for the Turkish version was .65, whereas the split-half reliability was .61 for depressive patients and .78 for students. By looking at BDI's correlation with Hamilton Depression Rating Scale (Hamilton, 1960), convergent validity of the scale was calculated as .75 (Hisli, 1988; 1989). The internal consistency reliability as measured by Cronbach's alpha was .89 for the present sample (See Appendix C).

3.2.2.3. The Caregiver Well-Being Scale (CWB Scale)

Caregiver Well-Being Scale was developed by Berg-Weber et al.(2000). This scale consists of two subscales, namely basic needs and activities of living. The basic needs subscale includes the physical needs like sleep and nutrition and some other needs like personal growth, relaxation and expression of feelings. The internal consistency reliability of this subscale was .91(Berg-Weger, Rubio, & Tebb, 2000). The second subscale, which is activities of living, includes the daily activities and some additional leisure activities like having a hobby. The internal consistency reliability of the activities of living subscale as measured by Cronbach's alpha was .81. The correlation coefficient between the two subscales was found as .69, indicating the convergent validity of the subscales (Berg-Weger, Rubio, & Tebb, 2000).

The Caregiver Well-Being Scale was adapted to Turkish by Demirtepe and Bozo (2009). Internal consistency reliability coefficients were .89 for the activities of living subscale and .93 for the basic needs subscale. Test-retest reliability of this scale was also strong (r = .79, p < .001). Caregiver Well Being Scale's divergent validity was assessed by its correlation with BDI (r = -.71, p < .01); and its convergent validity was assessed by its correlation by Mental, Physical and Spiritual Well-being Scale (MPSWS) (r = .55, p < .01) (Demirtepe & Bozo 2009). The internal consistency reliability as measured by Cronbach's alpha were .93 for basic needs subscale and .89 for activities of living subscale for the present sample (See Appendix D).

3.2.2.4. Positive and Negative Affect Schedule (PANAS)

PANAS, which was developed by Watson, Clark, and Tellegen (1988), has 20 items that constitute two subscales. The first subscale is positive affect, which consists of 10 items, and the second subscale negative affect also consists of 10 items. The PANAS was adapted to Turkish by Gençöz (2000). In this scale, respondents rate their affective states in the last two weeks. Cronbach's alpha coefficient for positive affect was reported as .83 and for negative affect it was reported as .86. Test-retest reliability for Turkish version was .40 and .54 for positive and negative affect, respectively. Positive affect's validity was assessed by its correlation with BDI (r = -.48, p < .001), and Beck Anxiety Inventory (r = -.22, p < .005). Moreover, negative affect's validity was also assessed by its correlation with BDI (r = .51, p < .001) and Beck Anxiety Inventory (r = .47, p < .001) (Gencoz, 2000). The internal consistency reliabilities as measured by Cronbach's alpha were .87 for positive affect and .86 for negative affect in the present study (See Appendix E).

3.2.2.5. Ways of Coping Inventory (WCI)

Ways of Coping Inventory was developed by Folkman and Lazarus (1980) and adapted to Turkish by Siva (1991) with the Cronbach's alpha coefficient .90. There are 74 items in the Turkish version of the scale. Hierarchical dimensions of coping styles were examined in the Gençöz, Gençöz, and Bozo study (2006), and three factors were identified; the problem focused, emotion focused, and indirect coping. The internal consistency reliabilities of the subscales were .90 for problem-focused coping, .88 for emotion-focused coping, and .84 for indirect coping. In this thesis, only problem focused coping and emotion-focused coping subscales were used (see Appendix G). Problem focused coping's validity was assessed by its correlation with sociotropy (r = -.23, p < .001), trait anxiety (r = -.62, p < .001), submissiveness (r = -.29, p < .001), and external locus of control (r = -.27, p < .001); and emotion-focused coping's validity was assessed by its correlation by sociotropy (r = .42, p < .001), trait anxiety (r = .17, p < .05), submissiveness (r = .45, p < .001), external locus of control (r = .25, p < .001); and the autonomy measure (r = -.18, p < .05). (Gencoz, Gencoz, & Bozo, 2006). The internal consistency reliability as measured by Cronbach's alpha was .92 for problem-focused coping subscale and .85 for emotion-focused coping subscales for the present sample (See Appendix F).

3.2.2.6. Multidimensional Scale of Perceived Social Support (MSPSS)

Multidimensional Scale of Perceived Social Support was developed by Zimet, Dahlem, Zimet, and Farley (1988) and adapted to Turkish by Eker and Arkar (1995). (See Appendix G). There are 12 items in this scale measuring perceived social support. The scale includes three subscales, namely support from family, support from friends, and support from significant others. The items are rated on a 7-point Likert type scale ranging between 7 (agree very strongly) and 1 (disagree very strongly). Lower scores on this scale mean lower levels of perceived social support. Test- retest reliability of the MSPSS was.85 (Zimet et al., 1988) and Cronbach’s alpha reliability coefficient for the 12 items as .93; and for the subscales of family, friends, and significant other as .91, .89, and .91, respectively (Canty-Mitchell & Zimet, 2000). Moreover, MSPSS’s construct validity was assessed by its correlation with Adolescent Family Caring Scale (AFCS), which were .76 for the family subscale, .33 for the friends subscale, and .48 for the significant other subscale ($p < .001$). The internal consistency reliability as measured by Cronbach's alpha was .94 for the present sample.

3.2.2.7. General Self-Efficacy Scale (GSE)

General Self-Efficacy Scale was developed by Jerusalem and Schwarzer in 1979 (1995). In the first version of the GSE, there were 20 items. In their 1981 study, Jerusalem and Schwarzer reduced the number of items to 10. GSE generally yields internal consistencies between .75 and .91 (Scholz, Doña, Sud, & Schwarzer, 2002). GSE was adapted to Turkish by Aypay (2010) with the overall alpha internal consistency of .83 and test-retest reliability of .80. In the Turkish GSE, there are two factors, effort and resistance and ability and confidence. The response scale of General Self-Efficacy Scale ranges from exactly true (4) to not at all true (1). Problem focused coping’s validity was assessed by its correlation with depression ($r = .52$, $p < .001$) and state-trait anxiety inventory ($r = .48$, $p < .001$) (Bourland et al., 2000). The internal consistency reliability as measured by Cronbach's alpha was .86 for the present sample (See Appendix H).

3.2.2.8. Autism Behavior Checklist (ABC)

Autism Behavior Checklist (Krug, Arick, & Almond 2008) has been developed by Krug, Arick, and Almond in 1978, then revised twice in 1993 and 2008. The latest revision of Autism Behavior Checklist has been used in this thesis. According to reliability and validity studies, ABC has .88 internal consistency, .99 test- retest reliability for professionals, and .76 test-retest reliability for parents. ABC was adapted to Turkish by Ozdemir and colleagues (2013). In the Modified Turkish Version of Autism Behavior Checklist (MTV-ABC), there are 57 behaviors rated by a person who is well acquainted with the individual diagnosed with autism spectrum disorder. The 57 behaviors are rated as 1 (Yes) if the individual shows this behavior and as 0 (No) if the individual does not show this behavior. Thus, in the present study higher scores on ABC means higher autism related behaviors/behavioral problems. Test-retest reliability of ABC was .73 correlation coefficient for parents and .69 for professionals. Moreover, in terms of criterion related validity, there was a significant correlation ($r = .67, p < .01$) between ABC and Gilliam Autism rating Scale-2-Turkish Version. The internal consistency reliability as measured by Cronbach's alpha was .88 for the present sample (See Appendix I).

3.2.2.9. The Index for Adaptation of Caregivers of Children with Autism Spectrum Disorder:

In order to assess caregivers' adaptation to changes after their child’s autism spectrum disorder diagnosis, an index with 53 questions were generated and four experts (one associate professor of psychology, two psychology Ph.D. students, and a psychology M.S. student) gave feedbacks on these questions. The questions were prepared based on the integrative coping model of Holahan and Moos (2007). Thus, theoretically the questions were believed to assemble under 7 factors, namely; *managing symptoms, managing treatment, developing and maintaining adequate relationships with health-care providers, managing emotions, maintaining a positive self-image, relating to family members and friends and preparing for an uncertain future* (See Appendix J).

(see results section for psychometric properties of Caregiver Adaptation Scale for Autism).

3.2.3. Procedure

Ethical permissions of the study were granted from Middle East Technical University (METU) Ethics Committee for Studying with Human Subjects. Participants of the study were reached through a world-wide-web based data collection tool (Qualtrics) and they were contacted via face-to-face meetings. Participants were informed prior to their participations to the study, and their consents were acquired. The questionnaires were completed in approximately 40 minutes. The order of scales was counter-balanced.

3.3. Results

3.3.1. Group Comparisons

In order to examine the differences among the levels of demographic variables on the measures of the study, series of one-way Analyses of Variances (ANOVA) and independent samples *t*-tests were conducted. To examine whether there were significant gender differences in terms of dependent variables of the study, an independent samples *t*-test was conducted. The independent samples *t*-test indicated that there was a significant difference between female and male participants on Autism Behavior Checklist (ABC) scores ($t(70) = 2.01$, $p < .05$). Female participants (*m* = 33.97, *sd* = 9.01) reported significantly higher scores on ABC than male participants (*m* = 28.15, *sd* = 11.22), which means that female caregivers reported more autism related behaviors than male caregivers. Males and females did not significantly differ on any other variable (i.e., depression, adaptation, coping, well-being, positive and negative affect).

In order to examine the differences between the levels of marital status on the dependent variables of the study, an independent samples *t*-test was conducted. The independent samples *t*-test indicated that there was a significant difference between single and married participants on emotion-focused coping scores (*t*(70) = 2.00, *p* < .05). Married participants (*m* = 55.45, *sd* = 9.20) reported significantly higher scores on emotion-focused coping subscale of WCI than single participants (*m* = 49.25, *sd* = 12.46). Single and married participants did not significantly differ on any other variable (i.e., depression, adaptation, well-being, positive and negative affect).

For education levels, one way Analyses of Variances (ANOVA) were conducted, but according to results of one way ANOVA, there were not any study variable that significantly differ among the levels of education.

In order to examine differences among SES levels on the measures of the study, one way ANOVA was conducted. The analysis yielded a significant result for Beck Depression Inventory (BDI) (*F*(2, 69) = 6.80, *p* < .01). The post hoc analysis showed that caregivers who reported themselves as a member of low SES (*m* = 24.20, *sd* = 11.59) had significantly higher BDI scores than participants who reported themselves as members of middle SES (*m* = 12.80, *sd* = 7.92) or high SES (*m* = 15.85, *sd* = 10.46). However, BDI scores of middle SES group and high SES group was not significantly different. Moreover, the analysis yielded a significant result for positive affect (PA), *F*(2, 69) = 4.45, *p* < .05. According to results of one way ANOVA, participants who reported themselves as a member of middle SES (*m* = 31.90, *sd* = 7.26) had significantly higher positive affect (PA) scores than both low SES group (*m* = 26.89, *sd* = 5.23) and high SES group (*m* = 25.14, *sd* = 5.52).

On the other hand, PA scores of low SES group and high SES group was not significantly different from each other. The result of one way ANOVA that examined the differences among SES levels in terms of negative affect (NA) was also marginally significant *F*(2, 69) = 3.13, *p* = .05). According to post hoc analysis, middle SES group's NA scores (*m* = 20.78, *sd* = 7.00) was significantly lower than both high SES group (*m* = 24.28, *sd* = 8.11) and low SES group (*m* = 26.55, *sd* = 5.63).

There was also a significant difference between participants who received support for caregiving and who did not receive any support in terms of basic needs subscale of Caregiver Well-Being Scale (*t*(70) = 2.43, *p* < .05). The caregivers who reported that they receive support for caregiving (*m* = 72.86, *sd* = 13.87) had significantly higher basic needs score than caregivers who reported that they did not receive any support (*m* = 64.20, *sd* = 16.20). In other words, the ones who reported that they receive support for caregiving, met their basic needs more. Likewise, in terms Multidimensional Scale of Perceived Social Support, there was a significant difference between participants who received support for caregiving and who did not receive any support, (*t*(70) = 2.96, *p* < .01). The caregivers who reported that they receive support for caregiving (*m* = 59.79, *sd* = 17.59) perceived significantly higher support than caregivers receiving no support (*m* = 46.80, *sd* = 19.40).

In order to investigate the differences between the caregivers having an only child with autism spectrum disorder diagnosis and having more than one child on the continuous variables of the study, an independent samples *t*-test was conducted. According to independent *t*-test results, there was a marginally significant difference between participants who had only one child and who have more than one child on Autism Behavior Checklist (ABC), (*t*(70) = 1.95, *p* = .54). The caregivers who had only one child (*m* = 36.00, *sd* = 7.93) reported significantly higher ABC scores than caregivers who have more than one child (*m* = 31.38, *sd* = 10.10), which means that the caregivers who had only one child, reported more autism related behaviors of their children than caregivers who had more than one child.

In order to examine whether there were significant differences between the participants with and without physical illness in terms of study variables, an independent samples *t*-test was conducted. The independent samples *t*-test indicated a significant difference on Autism Behavior Checklist (ABC) ($t(70) = -2.09$, $p < .05$). The caregivers who reported that they had a physical illness ($m = 27.45$, $sd = 4.93$) had significantly lower ABC scores than caregivers who reported that they did not have any physical illness ($m = 33.90$, $sd = 9.97$). In other words, caregivers who had a physical illness expressed more autism related behaviors of their children than caregivers who did not have a physical illness.

Lastly, to examine whether there were significant differences between the participants with and without psychological illness in terms of study variables, an independent samples *t*-test was conducted.. The independent samples *t*-test indicated that there were some significant differences between participants who had a psychological disorder and who did not have a psychological disorder on BDI scores ($t(70) = 5.44$, $p < .001$), activities of living scores ($t(70) = -2.92$, $p < .01$), ABC scores ($t(70) = -1.98$, $p = .52$), problem-focused coping scores ($t(70) = -3.72$, $p < .001$), emotion-focused coping scores ($t(70) = -2.88$, $p < .01$), positive affect scores ($t(70) = -2.69$, $p < .01$), negative affect scores ($t(70) = 3.31$, $p = .001$), and self-efficacy scores ($t(70) = -3.58$, $p = .001$). The caregivers who had a psychological disorder ($m = 25.30$, $sd = 9.57$) reported significantly higher BDI scores than caregivers who did not have any psychological disorder ($m = 12.14$, $sd = 7.50$). Moreover, the caregivers with a psychological disorder ($m = 54.21$, $sd = 13.15$) reported significantly lower activities of living scores than caregivers without psychological disorders ($m = 67.20$, $sd = 14.75$). Furthermore, the caregivers who had a psychological disorder ($m = 28.23$, $sd = 8.97$) reported significantly higher ABC scores than caregivers who did not have any psychological disorder (*m* = 33.95, *sd* = 9.54). For problem focused coping strategies, the caregivers who had a psychological disorder (*m* = 90.54, *sd* = 13.02) reported significantly lower PFC strategies than caregivers who did not have any (*m* = 107.38, *sd* = 15.07). Likewise, for emotion focused coping strategies, the caregivers who had a psychological disorder (*m* = 47.53, *sd* = 13.02) reported significantly lower EFC strategies than caregivers who did not have any psychological disorder (*m* = 55.94, *sd* = 9.06). For positive affect, the caregivers who had a psychological disorder (*m* =25.92, *sd* = 5.69) reported significantly lower PA than caregivers who did not have any psychological disorder (*m* = 31.64, *sd* = 7.18). In a similar vein, the caregivers who had a psychological disorder (*m* = 27.46, *sd* = 7.43) reported significantly higher NA scores than caregivers who did not have any psychological disorder (*m* = 20.61, *sd* = 6.55). Lastly, the caregivers who had a psychological disorder (*m* = 27.77, *sd* = 4.24) reported significantly lower self-efficacy scores than caregivers without any psychological disorder diagnosis (*m* = 31.58, *sd* = 3.29) (See Table 3.2.2.)

Table 3.3.1.1. *Descriptive Statistics and Mean Differences of Demographic Characteristics of Participants*

Variables	BDI					Perceived Social Support				
	M	*SD*	*df*	*t*	*F*	*M*	*SD*	*df*	*t*	*F*
Gender			70	.157	---			70	1.08	---
Female	14.61	9.36				55.52	18.97			
Male	14.15	9.67				49.15	20.92			
Education			2,69	---	.29			2,69	---	.836
Lower than High School	16.69	9.74				60.45	9.40			
High School	15.20	10.19				49.53	20.37			
Higher than High School	14.02	9.18				54.98	20.00			
Marital Status			70	-.23	---			70	1.34	---
Married	14.41	9.41				55.74	20.37			
Single	15.08	9.41				47.58	11.37			
Number of Children			70	-.39	---			70	.96	---
One	13.92	8.58				57.46	19.03			
More than one	14.83	9.79				52.84	19.51			
Perceived SES			2,69	---	6.80**			2,69	---	.46
Low	24.21	11.59				48.80	24.51			
Middle	12.80	7.92				54.95	18.22			
High	15.86	10.46				57.00	22.89			
Physical Illness			70	1.27	---			70	-.90	---
Yes	17.82	10.76				49.55	16.23			
No	13.93	9.04				55.25	19.84			
Psychological Disorder			70	5.44***	---			70	-1.40	---
Yes										
No										
Support for Caregiving			70	-.36	---			70	2.96**	
Yes	14.19	9.84				59.79	17.59			
No	15.00	8.75				46.80	19.41			

Table 3.3.1.1. *(Continued)*

Variables	NA					PA				
	M	*SD*	*df*	*t*	*F*	*M*	*SD*	*df*	*t*	*F*
Gender			70	.59	---			70	-.30	---
Female	21.73	7.44				30.85	7.24			
Male	22.38	6.08				29.54	7.45			
Age										
Education			2,69	---	.43			2,69	---	.29
Lower than High School	21.14	7.65				31.14	5.76			
High School	20.47	5.83				29.33	7.78			
Higher than High School	22.36	7.54				30.92	7.35			
Marital Status			70	-1.01	---			70	-.03	---
Married	21.47	7.39				30.60	7.02			
Single	23.75	5.86				30.67	8.60			
Number of Children			70	-1.23	---			70	-1.10	---
One	20.38	5.91				29.29	5.72			
More than one	22.58	7.68				31.27	7.87			
Perceived SES			2,69	---	3.13*			2,69	---	4.45**
Low	26.56	5.64				26.89	5.23			
Middle	20.79	7.01				31.89	7.26			
High	24.29	8.12				25.14	5.52			
Physical Illness			70	.76	---			70	.37	---
Yes	23.36	8.36				31.36	8.23			
No	21.57	6.98				30.48	7.12			
Psychological Disorder			70	3.33***	---			70	-2.69**	---
Yes	25.31	9.57				47.62	16.42			
No	12.15	7.50				55.87	19.74			
Support for Caregiving			70	.61	---			70	.21	---
Yes	22.29	7.40				30.76	7.47			
No	21.23	6.93				30.40	7.03			

Table 3.3.1.1. *(Continued)*

Variables	Adaptation to Health Related Changes					Adaptation to Daily Changes				
	M	*SD*	*df*	*t*	*F*	*M*	*SD*	*df*	*t*	*F*
Gender			70	.199	---			70	.939	
Female	88.19	12.82				77.24	14.10			
Male	87.38	14.74				72.62	23.35			
Education			2,69	---	1.01			2,69	---	.154
Lower than High School	87.29	17.22				76.86	7.13			
High School	83.93	16.34				74.33	21.93			
Higher than High School	89.38	11.33				76.96	15.10			
Marital Status			70	-.61	---			70	1.02	---
Married	87.62	13.88				77.27	16.65			
Single	90.17	8.10				72.08	12.32			
Number of Children			70	-.08	---			70	.41	---
One	87.88	9.89				77.50	13.51			
More than one	88.13	14.51				75.85	17.29			
Perceived SES			2,69	---	.32			2,69	---	.58
Low	85.11	15.10				80.00	13.43			
Middle	88.25	13.29				77.23	16.14			
High	90.14	9.19				76.71	19.26			
Physical Illness			70	1.87	---			70	-.44	---
Yes	94.73	8.82				74.45	14.24			
No	86.84	13.41				76.75	16.44			
Psychological Disorder			70	-1.23	---			70	-1.62	---
Yes	84.00	13.98				69.92	10.48			
No	88.93	12.83				77.83	16.77			
Support for Caregiving			70	-.76	---			70	.51	---
Yes	87.05	12.76				77.21	16.00			
No	89.43	13.61				75.27	16.33			

Table 3.3.1.1. *(Continued)*

Variables	Activities of Living					Basic Needs				
	M	*SD*	*df*	*t*	*F*	*M*	*SD*	*df*	*t*	*F*
Gender										
Female	65.97	15.22				69.29	15.15			
Male	59.77	14.83				69.08	17.10			
Education			2,69	---	.21			2,69	---	1.63
Lower than High School	68.23	10.43				63.88	10.83			
High School	63.78	15.82				64.60	15.00			
Higher than High School	64.70	15.80				71.40	15.78			
Marital Status			70	-.20	---			70	.41	---
Married	64.69	15.15				69.59	14.89			
Single	65.65	16.35				67.58	18.34			
Number of Children			70	.56	---			70	-.52	---
One	66.29	17.80				67.92	16.71			
More than one	64.13	13.93				69.92	14.82			
Perceived SES			2,69	---	.46			2,69	---	2.00
Low	60.26	13.07				59.80	15.27			
Middle	65.54	15.02				70.57	14.85			
High	65.29	20.35				70.86	17.84			
Physical Illness			70	-1.57	---			70	-.33	---
Yes	58.27	12.40				67.82	15.12			
No	66.03	15.48				69.51	15.55			
Psychological Disorder			70	-2.92**	---			70	-1.49	---
Yes	54.21	13.15				63.54	21.88			
No	67.20	14.75				70.51	13.49			
Support for Caregiving			70	.68	---			60	2.43*	---
Yes	65.89	13.95				72.86	13.87			
No	63.40	17.02				64.20	16.21			

Table 3.3.1.1. *(Continued)*

Variables	Self-Efficacy					Autism Behavior Checklist				
	M	*SD*	*df*	*t*	*F*	*M*	*SD*	*df*	*t*	*F*
Gender								70	2.01*	---
Female	30.92	3.80				33.97	9.02			
Male	30.77	3.65				28.15	11.22			
Education			2,69	---	.04			2,69	---	.91
Lower than High School	31.29	2.29				28.61	5.52			
High School	30.80	2.65				34.53	12.59			
Higher than High School	30.86	4.20				33.04	9.06			
Marital Status			70	.89	---			70	-.65	---
Married	31.07	3.78				32.59	10.06			
Single	30.00	3.62				34.58	7.23			
Number of Children			70	-.82	---			70	1.96*	---
One	30.38	3.17				36.00	7.93			
More than one	31.15	4.01				31.38	10.11			
Perceived SES			2,69	---	.59			2,69	---	1.18
Low	31.22	3.46				29.03	9.84			
Middle	31.02	3.73				33.13	9.60			
High	29.43	4.47				36.29	9.43			
Physical Illness			70	.02	---			70	-2.09*	---
Yes	30.91	5.17				27.45	4.93			
No	30.89	3.49				33.91	9.97			
Psychological Disorder			70	-3.58***	---			70	-1.98*	---
Yes	27.77	4.25				28.23	8.97			
No	31.58	3.29				33.95	9.54			
Support for Caregiving			70	-1.50	---			70	1.26	---
Yes	30.33	3.55				34.13	9.40			
No	31.67	3.94				31.23	9.87			

Table 3.3.1.1. *(Continued)*

Variables	Problem-Focused Coping					Emotion-Focused Coping				
	M	*SD*	*df*	*t*	*F*	*M*	*SD*	*df*	*t*	*F*
Gender			70	.12	---			70	.69	---
Female	104.45	16.33				54.80	9.73			
Male	103.85	15.22				52.69	11.41			
Education			2,69	---	.92			2,69	---	1.80
Lower than High School	98.65	13.83				60.78	13.73			
High School	108.33	17.19				52.33	6.20			
Higher than High School	103.94	15.96				54.16	10.18			
Marital Status			70	-.37	---			70	2.01*	---
Married	104,03	16.59				55.46	9.21			
Single	105.92	13.41				49.25	12.47			
Number of Children			70	-.78	---			70	-.43	---
One	102.25	12.45				53.71	9.37			
More than one	105.39	17.58				54.78	10.38			
Perceived SES			2,69	---	1.90			2,69	---	.99
Low	96.73	17.58				50.71	10.49			
Middle	106.27	15.77				55.29	10.34			
High	98.71	13.83				52.29	4.75			
Physical Illness			70	-.16	---			70	-1.13	---
Yes	103.64	16.01				51.27	11.94			
No	104.47	16.16				54.99	9.61			
Psychological Disorder			70	-3.73***	---			70	-2.88**	
Yes	90.54	13.03				47.54	11.49			
No	107.38	15.08				55.94	9.06			
Support for Caregiving			70	.76	---			70	-.63	---
Yes	105.56	15.82				53.80	10.25			
No	102.64	16.44				55.30	9.73			

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

3.3.2. Psychometric properties of Caregiver Adaptation Scale for Autism (CASA)

Barlett's test of sphericity was significant ($\chi 2$ = 2766.85, *df* = 903, *p* < .001) and the Kaiser–Meyer–Olkin value was .718, suggesting that the items of Caregiver Adaptation Scale for Autism (CASA) were appropriate for factor analysis. Fifty-three items of the CASA were subjected to factor analysis by using varimax rotation and forced to two factors. Eight of the items were not loaded to any of the factors. After deleting these eight items, CASA were again subjected to factor analysis by using varimax rotation and forced to two factors. Two of the items were not loaded to theoretically appropriate factors. Therefore, these two items were also deleted from the scale. Consequently, 10 of the 53 items were discarded from the scale because of low factor loadings, theoretical problems, or unloading to a factor. For these factors, the eigenvalues were 11.75 and 4.95, respectively. The amounts of variance explained by these factors were 27.33 % and 11.52 %, respectively. Thus, these 2 factors totally explained 38.85 % of the variance. The cut-off score for the item loadings was considered as .30. According to this criterion, 19 items constituted the first factor (i.e., items related to managing symptoms, managing treatment, and developing and maintaining adequate relationships with health-care providers), which was labeled as "adaptation to health related changes". The adaptation to health related changes factor revealed an alpha coefficient of .894. The second factor, which was named as "adaptation to daily changes" (i.e., items related to maintaining of a positive self-image, relating to family members and friends, and preparing for an uncertain future), consisted of 24 items with an alpha coefficient of .903 (See Table 3.3.1.)

Table 3.3.2.1. *Factor loadings, explained variances and alpha coefficients for Caregiver Adaptation Scale for Autism (CASA)*

Item	Factors		Corrected Item-total Correlation	Cronbach's Alpha if Item Deleted
	Adaptation to Health Related Changes	Adaptation to Daily Changes		
Q11 (Çocuğum kendine şiddet gösterdiğinde bunun sebebini anlayabiliyorum)	**.717**	-.104	.668	.884
Q10 (Çocuğum kendine şiddet gösterdiğinde bununla başa çıkabiliyorum)	**.713**	.036	.644	.885
Q14 (Çocuğum bir başkasına şiddet gösterdiğinde bunun sebebini anlayabiliyorum)	**.712**	.009	.623	.886
Q3 (Çocuğumun isteklerini karşılayabiliyorum)	**.708**	.073	.658	.886
Q6 (Çocuğum ağladığında bunun sebebini anlayabiliyorum)	**.675**	.086	.646	.886
Q5 (Çocuğumun davranış problemi göstereceği zamanları önceden anlayabiliyorum)	**.671**	.026	.627	.886
Q9 (Çocuğum bağırdığında bununla başa çıkabiliyorum)	**.665**	.122	.604	.887
Q8 (Çocuğum bağırdığında bunun sebebini anlayabiliyorum)	**.661**	.058	.602	.887
Q21 (Çocuğumun hangi alanlarda eğitime ihtiyaç duyduğunu anlayabiliyorum)	**.660**	.177	.585	.887
Q12 (Çocuğum bana şiddet gösterdiğinde bununla başa çıkabiliyorum)	**.659**	.043	.574	.887
Q2 (Çocuğumun ihtiyaçlarını anlayabiliyorum)	**.602**	-.018	.528	.889
Q20 (Çocuğumun daha iyi bir eğitim alması ile ilgili neler yapacağımı biliyorum)	**.577**	.147	.535	.889
	.573	.200	.496	.890

Table 3.3.2.1. *(Continued)*

Item	Factors		Corrected Item-total Correlation	Cronbach’s Alpha if Item Deleted
	Adaptation to Health Related Changes	Adaptation to Daily Changes		
Q19 (Çocuğumun ihtiyacı olan eğitim için gerekli kaynaklara ulaşabiliyorum)	**.502**	.417	.504	.890
Q16 (Çocuğumun (eğer alıyorsa) özel eğitim sürecine uyum sağlayamadım)	**.444**	.130	.493	.890
Q24 (Çocuğumun öğretmeni ile istediğim gibi iletişim kurabiliyorum)	**.392**	.161	.391	.893
Q25 (Çocuğumun öğretmenine isteklerimi ifade edemiyorum)	**.340**	.-091	.316	.897
Q4 (Çocuğumun ihtiyaçlarını karşılayamıyorum)	**.339**	.131	.324	.895
Q22 (Doktor kontrollerine ve rapor alma-yenileme süreçlerine uyum sağlayamadım)	**.321**	.080	.320	.890
Q42 (Kök ailem (kendi anne-babam ve kardeşlerim) ile yaşadığım problemleri sağlıklı bir şekilde çözebiliyorum)	.166	**.798**	.743	.894
Q39 (Kök ailem (kendi anne-babam ve kardeşlerim) ile ilişkilerimi sağlıklı bir şekilde sürdürebiliyorum)	.154	**.770**	.703	.895
Q41 (Çekirdek ailem (eşim ve diğer çocuklarım) ile yaşadığım problemleri sağlıklı bir şekilde çözebiliyorum)	.189	**.664**	.603	.897
Q40 (Çekirdek ailem (eşim ve diğer çocuklarım) ile ilişkilerimi sağlıklı bir şekilde sürdürebiliyorum)	.093	**.655**	.551	.898
Q47 (Arkadaşlarımla ilişkilerim sağlıklı bir şekilde sürdürebiliyorum)	.180	**.652**	.604	.897
Q44 (Çekirdek ailemden (eşim ve diğer çocuklarım) beklediğim desteği onlara ifade edebiliyorum)	.167	**.648**	.590	.898
Q38 (Dış görünüşüme özen gösterebiliyorum)	.350	**.633**	.697	.895

Table 3.3.2. 1. *(Continued)*

Item	Factors		Corrected Item-total Correlation	Cronbach's Alpha if Item Deleted
	Adaptation to Health Related Changes	Adaptation to Daily Changes		
Q48 (Arkadaşlarımdan beklediğim desteği onlara ifade edebiliyorum)	.208	**.618**	.589	.898
Q53 (Çocuğumun gelecekte ihtiyaç duyabileceği bakım için gerekli hazırlıkları yapabiliyorum)	.305	**.612**	.639	.897
Q49 (Arkadaşlarımdan beklediğim desteği alabiliyorum)	-.008	**609**	.516	.899
Q43 (Kök ailemden (kendi anne-babam ve kardeşlerim) beklediğim desteği onlara ifade edebiliyorum)	.110	**.605**	.549	.898
Q52 (Çocuğumun gelecekte karşılaşabileceği ekonomik zorluklar için gerekli hazırlığı yapabiliyorum)	.361	**.585**	.613	.897
Q46 (Kök ailemden (kendi anne-babam ve kardeşlerim) beklediğim desteği alamıyorum)	-.207	**.535**	.397	.901
Q35 (Kendi öz bakımımı istediğim şekilde sağlayabiliyorum)	.206	**.519**	.549	.898
Q32 (Otizm spektrum bozukluğu tanısı almış bir çocuğun ebeveyni olarak duygusal ihtiyaçlarımı karşılayamıyorum)	.141	**.518**	.513	.899
Q51 (Çocuğumun gelecekte alması gereken eğitim için gerekli hazırlığı yapabiliyorum)	.460	**.516**	.564	.898
Q50 (Çocuğumun gelecekte karşılaşabileceği sağlık problemleri için gerekli hazırlığı yapabiliyorum)	.487	**.510**	.588	.897
Q45 (Çekirdek ailemden (eşim ve diğer çocuklarım) beklediğim desteği alamıyorum)	-.016	**.491**	.401	.901
Q37 (Kendimden hoşnutum)	.579	**.491**	.604	.897
Q34 (Kendime istediğim kadar vakit ayıramıyorum)	-.154	**.467**	.376	.902
Q36 (Fiziksel sağlığıma dikkat edemiyorum)	-.132	**.435**	.353	.902
Q30 (Otizm spektrum bozukluğu tanısı almış bir çocuğun ebeveyni olarak olumsuz duyguların yarattığı etkileri kontrol edebiliyorum)	.535	**.407**	.517	.899
Q33 (Kendi fiziksel bakımımı istediğim şekilde sağlayabiliyorum)	-.020	**.332**	.279	.920
Q31 (Otizm spektrum bozukluğu tanısı almış bir çocuğun ebeveyni olarak olumsuz duygularımla başa çıkamıyorum)	.330	**.325**	.390	.901

Table 3.3.2.1. (Continued)

	Factors		Corrected	Cronbach's
Item	Adaptation to Health Related Changes	Adaptation to Daily Changes	Item-total Correlation	Alpha if Item Deleted
Eigen Values	11.75	.4.95		
Explained Variance (%)	27.33	11.52		
Alpha coefficient	.894	.903		

Note. Items that were loaded to a factor were shown in bold characters under the respective factor

The *adaptation to health related changes* factor was significantly and negatively correlated with depressive symptoms ($r = -.35$, $p < .05$) and negative affect ($r = -.35$, $p < .05$). Moreover, it was significantly correlated with self-efficacy ($r = .42$, $p < .001$), positive affect ($r = .38$, $p = .001$), problem focused coping ($r = .45$, $p < .001$), emotion focused coping ($r = .25$, $p < .05$), basic needs ($r = .26$, $p < .05$) and activities of living subscales of Caregiver Well Being Scale ($r = .29$, $p < .05$).

The *adaptation to daily changes* factor was significantly correlated with basic needs ($r = .60$, $p < .001$) and activities of living ($r = .62$, $p < .001$) subscales of Caregiver Well Being Scale, perceived social support ($r = .51$, $p < .001$), problem focused coping ($r = .56$, $p < .001$), emotion focused coping ($r = .31$, $p < .05$), positive affect ($r = .47$, $p < .001$), and self-efficacy ($r = .27$, $p < .05$). Moreover, it was significantly and negatively correlated with negative affect ($r = -.55$, $p < .001$) and depressive symptoms ($r = -.64$, $p < .001$).

Table 3.3.2.2. *Pearson Correlation Coefficients among Variables*

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1.Age	-														
2. Age of Child	.589***	-													
3. Diagnosis age of child	.210	.324**	-												
4. Caregiving Duration	.568***	.972***	.093	-											
5. BDI	-.114	-.349**	-.055	-.35**	(.89)										
6. Basic Needs	.182	.155	-.106	.190	-.54***	(.93)									
7. Activities of Living	.167	.181	.022	.186	-.64***	.565***	(.89)								
8. Perceived Social Support	-.059	-.022	-.052	-.010	-.33**	.506***	.399***	(.94)							
9. ABC	-.131	-.087	-.180	-.047	-.24*	.179	.391***	.169	(88)						
10. Adaptation to Caregiving	.312**	.266*	.133	.247*	-.61***	.533***	.566***	.308**	.25*	(84)					
11.Problem-Focused Coping	.219	.298*	.201	.264*	-.64***	.356**	.400***	.222	.205	.600***	(.92)				
12.Emotion-Focused Coping	.069	.079	.167	.042	-.35**	.221	.283*	.173	.149	.3**	.44***	(.85)			
13.Positive Affect	.155	.231	.140	.208	-.59***	.414***	.466***	.246*	.106	.5***	.71***	.371***	(.87)		
14.Negative Affect	-.133	-.063	-.039	-.056	.653***	-.34**	-.57***	-.266*	-.2*	-.1***	-.5***	-.47***	-.47***	(86)	
15. Self-Efficacy	.093	.033	.275*	-.033	-.231	.027	.169	.013	.047	.4***	.58***	.359**	.521***	-.30**	(.86)

Note 1. $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$

Note 2. Scores within the parentheses on the diagonal represent the Cronbach’s alpha coefficients for the scales and subscales of the study

3.3.3. Hierarchical Regression Analyses for Positive Affect, Negative Affect, Depression, Activities of Living, and Basic Needs

Five hierarchical regression analyses were carried out to determine the predictors of positive affect, negative affect, depression, activities of living, and basic needs. The entry order of the variables was determined based on the model of Holahan and Moos (2007). The first panel consisted of demographic variables and self-efficacy of the caregiver. The second panel consisted of autism related behaviors. The third one consisted of perceived social support. The fourth one consisted of adaptation to caregiving activities. The fifth one consisted of coping strategies, and at the last panel represents the outcome variables, which were depressive symptoms, positive and negative affect, and caregiver well-being indicators, i.e., the extent to which the caregivers perform activities of living and meet their basic needs. Cognitive appraisal, which is originally a component of Holahan and Moos' integrative coping model (2007), was not taken into consideration in present study.

The first hierarchical regression analysis was conducted using positive affect as the criterion, and psychological disorder of caregiver as the first step predictor. Gender, age, SES, education, perceived social support, general self-efficacy, and child's behaviors related to autism spectrum disorder obtained through ABC were the second step predictors. Adaptation to caregiving was the third step predictor and coping styles were the fourth step predictors. In the first step, psychological disorder explained 9.4 % of the variance in positive affect ($R^2 = .09$, $F(1, 70) = 7.22$, $p < .01$). According to regression analysis, psychological disorder ($\beta = -.31$, $p < .01$) was negatively associated with positive affect. In other words, having been diagnosed with a psychological disorder predicted less positive affect in caregivers of autistic children. The addition of gender, age, SES, perceived social support, general self-efficacy, and child's behaviors related to autism spectrum disorder in the second step led to an increment in explained variance by 26.6 % in positive affect (R^2 = .36, F(8, 63) = 4.43, p < .001). While gender (β = -.05, p = .65), age (β = .16, p = .16), education (β = -05, p = .67), SES (β = -.05, p = .68) and child's behaviors related to autism spectrum disorder (β = .03, p = .76) were not significantly related to positive affect, general self efficacy (β = .45, p < .001) and perceived social support (β = .22, p < .05) were positively associated with positive affect. Thus, after controlling for the effect of psychological disorder, higher self-efficacy and higher perceived social support predicted more positive affect in caregivers of autistic children. The addition of adaptation to caregiving obtained through Caregiver Adaptation Scale for Autism in the third step led to an increment in explained variance by 5.5 % in positive affect (R^2 = .42, F(9, 62) = 4.88, p < .001). Adaptation to caregiving (β = .30, p < .05) was positively associated with positive affect. In other words, after controlling for the effect of psychological disorder, self-efficacy and perceived social support, higher adaptation predicted more positive affect in caregivers of children with autism spectrum disorder. The addition of problem focused coping and emotion focused coping in the last step let to an increment in explained variance by 13.5 % in positive affect (R^2 = .55, F(11, 60) = 6.58, p < .001). While emotion-focused coping (β = .05, p = .62) was not significantly related to positive affect, problem focused coping was positively associated with positive affect (β = .53, p < .001) Thus, after controlling for the effect of psychological disorder, self-efficacy, perceived social support and adaptation to caregiving, higher problem focused coping strategies predicted more positive affect in caregivers of children with autism spectrum disorder (see Table 3.3.2.1.).

Table 3.3.3.1. *Hierarchical Regression Analysis for Predicting Positive Affect*

	ΔF	*df*	*t*	β	R^2
First step	7.22	1,70			.094
Psychological Disorder			-2.69	-.306**	
Second Step	3.75	7,63			.360
Gender			-.453	-.048	
SES			-.416	-.047	
Perceived Social Support			2.15	.224*	
Age			1.44	.156	
Child's behaviors (ABC)			.302	.033	
Education			.429	.048	
Self-Efficacy			3.946	.450***	
Third Step	5.77	1,62			.415
Adaptation to Caregiving			2.402	.300*	
Fourth Step	8.725	2,60			.547
Emotion-Focused Coping			.504	.051	
Problem-Focused Coping			4.005	.528***	

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

A similar procedure was followed to test the hypotheses about negative affect. Psychological disorder of caregiver was the first step predictor at the hierarchical regression. Gender, age, SES, education, perceived social support, general self-efficacy, and child's behaviors related to autism spectrum disorder were the second step predictors. Adaptation to caregiving was the third step predictor and coping styles were the fourth step predictors. In the first step psychological disorder explained 13.7 % of the variance in negative affect ($R^2 = .14$, $F(1, 70) = 11.09$, $p = .001$). Psychological disorder ($\beta = .37$, $p = .001$) was positively associated with negative affect. In other words, existence of a psychological disorder predicted more negative affect in caregivers. The addition of gender, age, SES, perceived social support, general self-efficacy and child's behaviors related to autism spectrum disorder in the second step let to an increment in explained variance by 16 % in negative affect ($R^2 = .30$, $F(8, 63) = 3.31$, $p < .01$). According to results of hierarchical regression, age ($\beta = -.21$, $p = .06$), education ($\beta = .16$, $p = .18$), SES ($\beta = -.08$, $p = .51$), general self-efficacy ($\beta = -.19$, $p = .12$), perceived social support ($\beta = -.20$, $p = .07$), child's behaviors related to autism spectrum disorder ($\beta = -.18$, $p = .12$) and gender ($\beta = -.46$, $p = .68$) were not significantly related to positive affect. The addition of adaptation to caregiving in the third step let to an increment in explained variance by 11 % in negative affect ($R^2 = .41$, $F(9, 62) = 4.71$, $p < .001$). Adaptation to caregiving ($\beta = -.43$, $p < .001$) was negatively associated with negative affect. Thus, poor adaptation predicted more negative affect in caregivers. The addition of problem-focused coping and emotion-focused coping in the last step let to an increment in explained variance by 8 % in negative affect ($R^2 = .47$, $F(11, 60) = 4.85$, $p < .001$). However, both emotion-focused coping ($\beta = -.21$, $p = .06$) and problem-focused coping ($\beta =- .22$, $p = .13$) were not significantly related to negative affect (see Table 3.3.2.2.).

Table 3.3.3.2. *Hierarchical Regression Analysis for Predicting Negative Affect*

	ΔF	d*f*	*t*	β	R^2
First step	11.094	1,70			.124
Psychological Disorder			3.33	.37*	
Second Step	2.055	7,63			.297
Gender			-.414	-.046	
SES			-.664	-.079	
Perceived Social Support			-1.846	-.201	
Age			-1.932	-.219	
Child's behaviors (ABC)			-1.536	-.179	
Education			1.370	.162	
Self-Efficacy			-1.581	-.189	
Step 3	11.37	1,62			.406
Adaptation to Caregiving			-3.372	-.425*	
Step 4	3.66	2,60			.471
Emotion-Focused Coping			-1.958	-.214	
Problem-Focused Coping			-1.517	-.216	

Note. * $p < .001$

A similar procedure was followed to test the hypotheses about depression. Since age of children was a significant predictor of depression at the correlation analysis; in addition to psychological disorder of caregiver, the age of the autistic child was entered as another first step predictor in the hierarchical regression analysis. Gender, age, SES, education, perceived social support, general self-efficacy and child's behaviors related to autism spectrum disorder were the second step predictors. Adaptation to caregiving was the third step predictor, and coping styles were the fourth step predictors. In the first step psychological disorder and age of the autistic child explained 39 % of the variance in depression ($R^2 = .39$, $F(2, 69) = 22.19$, $p < .001$). While age of the child ($\beta = -.31$, $p < .01$) was negatively associated with depression, psychological disorder ($\beta = .52$, $p < .001$.) was positively associated. In other words, as the age of the child decreased and if the caregiver had a psychological disorder, they reported more depressive symptoms. The addition of gender, age, SES, perceived social support, general self-efficacy, and child's behaviors related to autism spectrum disorder in the second step let to an increment in explained variance by 12 % in negative affect ($R^2 = .51$, $F(9, 62) = 7.24$, $p < .001$). According to results of hierarchical regression analysis, age ($\beta = .03$, $p = .83$), education ($\beta = -.04$, $p = .68$), SES ($\beta = -.06$, $p = .53$), general self-efficacy ($\beta = -.06$, $p = .57$) and child's behaviors related to autism spectrum disorder ($\beta = -.16$, $p = .12$), and gender ($\beta = -.17$, $p = .09$) were not significantly related to depression. On the other hand, perceived social support ($\beta = -.26$, $p < .01$) was negatively associated with depression. In other words, after controlling for the effect of psychological disorder, higher perceived social support predicted less depressive symptoms in caregivers of children with autism spectrum disorder. The addition of adaptation to caregiving in the third step let to an increment in explained variance by 15 % in depression ($R^2 = .66$, $F(10, 61) = 12.81$, $p < .001$). Adaptation to caregiving ($\beta = -.50$, $p < .001$) was negatively associated with depression. Thus, higher adaptation predicted less depressive symptoms in caregivers of children with autism spectrum disorder. The addition of problem focused coping and emotion focused coping in the last step let to an increment in explained variance by 5 % in positive affect ($R^2 = .71$, $F(12, 59) = 11.95$, p

$< .001$). While emotion-focused coping ($\beta = -.03$, $p = .68$) were not significantly related to negative affect, problem focused coping ($\beta = -.33$, $p < .01$) was negatively associated with depression. In other words, after controlling for the effect of psychological disorder, perceived social support and adaptation, higher problem focused coping strategies predicted less depressive symptoms in caregivers of children with autism spectrum disorder (see Table 3.3.2.3.)

Table 3.3.3.3. *Hierarchical Regression Analysis for Predicting Depression*

	ΔF	*df*	*t*	β	R^2
First step	22.194	2,69			.391
Psychological Disorder			5.530	.521**	
Age of the Child with Autism Spectrum Disorder			-3.270	-.308*	
Second Step	2.203	7,62			.513
Gender			-1.734	-.174	
SES			-.639	-.064	
Perceived Social Support			-2.853	-.262*	
Age			.207	.026	
Child's behaviors (ABC)			-1.599	-.156	
Education			-.409	-.041	
Self-Efficacy			-.576	-.057	
Step 3	26.287	1,61			.659
Adaptation to Caregiving			-5.127	-.496**	
Step 4	4.974	2,59			.709
Emotion-Focused Coping			-.415	-.034	
Problem-Focused Coping			-2.997	-.331*	

Note. * $p < .01$, ** $p < .001$

The fourth hierarchical regression analysis was conducted using activities of living as the criterion, and psychological disorder of caregiver as the first step predictor. Gender, age, SES, education, perceived social support, general self-efficacy and child's behaviors related to autism spectrum disorder were the second step predictors. Adaptation to caregiving was the third step predictor, and coping styles were the fourth step predictors. In the first step psychological disorder explained 11 % of the variance in activities of living ($R^2 = .11$, $F(1, 70) = 8.56$, $p < .01$). Psychological disorder ($\beta = -.33$, $p < .01$) was negatively associated with activities of living. So, having no psychological disorder predicted better functioning in daily activities. The addition of gender, age, SES, perceived social support, general self-efficacy and child's behaviors related to autism spectrum disorder in the second step let to an increment in explained variance by 29 % in activities of living ($R^2 = .40$, $F(8, 63) = 5.20$, $p < .001$). While gender ($\beta = -.05$, $p = .61$), education ($\beta = -09$, $p = .42$), SES ($\beta = -.03$, $p = .81$), and general self efficacy ($\beta = .02$, $p = .88$) were not significantly related to activities of living, child's behaviors related to autism spectrum disorder ($\beta = .32$, $p < .01$), perceived social support ($\beta = .32$, $p < .01$), and age ($\beta = .30$, $p < .01$) was positively associated with activities of living. In other words, with the increase in age of caregivers and perceived social support, caregivers reported higher performance in activities of living. The addition of adaptation to caregiving in the third step let to an increment in explained variance by 9 % in activities of living ($R^2 = .49$, $F(9, 62) = 6.73$, $p < .001$). Adaptation to caregiving ($\beta = .40$, $p < .001$) was positively associated with activities of living. Thus, caregivers who adapted to caregiving better, have increased activities of living scores. The addition of problem focused coping and emotion focused coping in the last step did not let to an increment in explained variance in activities of living ($R^2 = .49$, $F(11, 60) = 5.33$, $p < .001$). Both emotion-focused coping ($\beta = .02$, $p = .83$) and problem-focused coping ($\beta = -.01$, $p = .99$) were not significantly related to activities of living (see Table 3.3.2.5.)

Table 3.3.3.4. *Hierarchical Regression Analysis for Predicting Activities of Living*

	ΔF	*df*	*t*	β	R^2
First step	8.558	1,70			.109
Psychological Disorder			-2.925	-.330*	
Second Step	4.311	7,63			.398
Gender			-.509	-.053	
SES			-.246	-.027	
Perceived Social Support			3.133	.316*	
Age			2.893	.304*	
Child's behaviors (ABC)			3.004	.319*	
Education			-.802	-.089	
Self-Efficacy			.145	.016	
Fourth Step	11.823	1,62			.494
Adaptation to Caregiving			3.438	.400**	
Fifth Step	.024	2,60			.494
Emotion-Focused Coping			.217	.023	
Problem-Focused Coping			-.008	-.001	

Note. * $p < .01$, ** $p < .001$

Lastly, a similar procedure was used to test the hypotheses about basic needs. Since having someone to support for caregiving activities was significantly correlated with basic needs at the correlation analysis, it was entered as the first step predictor at the hierarchical regression. Gender, age, SES, education, perceived social support, general self-efficacy, and child's behaviors related to autism spectrum disorder were the second step predictors. Adaptation to caregiving was the third step predictor, and coping styles were the fourth step predictors. In the first step, support for caregiving explained 8 % of the variance in basic needs (R^2 = .08, F(1, 70) = 5.93, p < .05). Support for caregiving (β = -.28, p < .05) was negatively associated with basic needs. In other words, caregivers who reported as having someone to support for caregiving, met less basic needs. The addition of gender, age, SES, perceived social support, general self-efficacy, and child's behaviors related to autism spectrum disorder in the second step let to an increment in explained variance by 27 % in basic needs (R^2 = .35, F(8, 63) = 4.36, p < .001). According to results of hierarchical regression, age (β = .20, p = .06), education (β = .13, p = .27), SES (β = -.03, p = .79), general self-efficacy (β = -.02, p = .83), child's behaviors related to autism spectrum disorder (β = -.10, p = .38), and gender (β = -.02, p = .89) were not significantly related to basic needs. On the other hand, perceived social support (β = .47, p < .001) was positively associated with basic needs. Thus, after controlling for the effect of having someone to support for caregiving, higher perceived social support predicted higher basic needs scores in caregivers of children with autism spectrum disorder. The addition of adaptation to caregiving in the third step let to an increment in explained variance by 13 % in basic needs (R^2 = .48, F(9, 62) = 6.41, p < .001). Adaptation to caregiving (β = .47, p < .001) was positively associated with basic needs. In other words, caregivers who had higher adaptation reported increased basic needs scores. The addition of problem focused coping and emotion focused coping in the last step let to an increment in explained variance by 1 % in basic needs (R^2 = .49, F(11, 60) = 5.33, p < .001). However, both emotion-focused coping (β = .09, p = .42) and problem-focused coping (β = .10, p = .50) were not significantly related to basic needs

Table 3.3.3.5. *Hierarchical Regression Analysis for Predicting Basic Needs*

	ΔF	*df*	*t*	β	R^2
First step	5.926	1,70			.078
Having Someone to Support for Caregiving			-2.434	-.279*	
Second Step	3.784	7,63			.351
Gender			.136	.015	
SES			.269	.031	
Perceived Social Support			4.219	.465**	
Age			1.393	.202	
Child's behaviors (ABC)			.893	.097	
Education			1.115	.126	
Self-Efficacy			.220	.023	
Third Step	15.710	1,62			.482
Adaptation to Caregiving			3.964	.467**	
Fourth Step	.719	2,60			.494
Emotion-Focused Coping			.285	.028	
Problem-Focused Coping			.416	.044	

Note. * $p < .05$, ** $p < .001$

Table 3.3.3.6. *Summary of the Results of Hierarchical Regression Models*

	Depressive Symptoms	Negative Affect	Positive Affect	Basic Needs	Activities of Living
First Step Variables					
Having Someone to Support for Caregiving				Significant(+)	
Psychological Disorder	Significant (+)	Significant (+)	Significant (-)		Significant (-)
Age of the Child with Autism Spectrum Disorder	Significant (-)				
Second Step Variables					
Gender					
SES					
Perceived Social Support	Significant (-)		Significant (+)	Significant (+)	
Age					Significant (+)
Child's behaviors (ABC)					Significant (+)
Education					
Self-Efficacy			Significant (+)		
Third Step Variables					
Adaptation to Caregiving	Significant (-)	Significant (-)	Significant (+)	Significant (+)	Significant (+)
Fourth Step Variables					
Emotion-Focused Coping					
Problem-Focused Coping	Significant (-)		Significant (+)		

Note. (-) for negatively associated and (+) for positively associated

3.4. Discussion

The aim of the Study 2 of this thesis was to examine the correlates of positive affect, negative affect, depressive symptoms, activities of living, and the basic needs of caregivers of children with autism spectrum disorder. In order to explore these associations, based on the model of Holahan and Moss (2007), 5 hierarchical regression analyses were conducted. The results of these hierarchical regressions will be discussed below.

3.4.1. Positive affect

The results of hierarchical regression analysis demonstrated that while having a psychological disorder was negatively associated with positive affect; after controlling for the effects of having a psychological disorder, general self-efficacy and perceived social support were still positively associated with positive affect. Moreover, after controlling the effects of causal antecedents (i.e., psychological disorder, general self-efficacy and perceived social support), adaptation to caregiving and problem-focused coping strategies were positively associated with positive affect.

As it was suggested in the literature, positive affect is negatively correlated with depression in a non-clinical Turkish sample (Gencoz, 2002). Therefore, the relation found between positive affect and having a psychological disorder in the current study was not surprising, since caregivers of children with autism spectrum disorder possess higher levels of chronic stress (Ruiz-Robledillo & Moya-Albiol, 2015), depression (Manning, Wainwright, & Bennett, 2010), and anxiety.

Again for perceived social support, the results were congruent with the literature, since depression, stress and anxiety were negatively correlated with social support (Falk, Norris, & Quinn, 2014). As a result of increased perceived social support; family functioning (Manning, Wainwright, & Bennett, 2010) and family quality of life (Pozo, Sarriá, & Brioso, 2013) can increase, which may, in turn, increase the positive affect score of caregivers.

General self-efficacy is another variable that was positively associated with positive affect. According to a study by Nair and Dovina (2015), self-efficacy has a significant influence on positive affect. Bandura (1995) described self-efficacy as the belief of a person in his/her ability to succeed in a particular situation, i.e., caregiving in this study. Therefore, the caregivers who have a belief in his/her ability to succeed in caregiving might have reported higher positive affect.

After controlling for the effects of causal antecedents (i.e., psychological disorder, general self-efficacy and perceived social support) adaptation to caregiving was also positively associated with positive affect. Adaptation to caregiving was measured by Caregiver Adaptation Scale for Autism (CASA), which was developed by the theoretical frame proposed by Holahan and Moos (2007). This scale consists of questions regarding the managing symptoms of autism spectrum disorder, managing treatment and education, forming relationships with health-care providers, managing emotions, maintaining a positive self-image, relating to family members and friends, and preparing for an uncertain future. Participants, who got a higher score on adaptation, also had higher positive affect scores. After autism spectrum disorder diagnosis, the life of a caregiver changes dramatically, and new tasks emerge. They have to follow a new daily routine where there is little time even for their basic needs, daily activities, and let alone for leisurely activities. Therefore, adaptation to this new daily routine and managing this routine might have increased the positive affect of caregivers of children with autism spectrum disorder.

Consistent with the literature (Dunkley & Lewkowski, 2016), at the last step of the hierarchical regression analysis problem-focused coping strategies were also positively associated with positive affect. It was revealed that mother caregivers who utilize more problem-focused coping strategies reported higher levels of well-being (Benson, 2010; Pozo, Sarriá, & Brioso, 2013), less perceived stress, and less perceived child behavioral problems as well as increased daily positive mood, lower depressive symptoms, and higher parental satisfaction. Therefore, the use of problem-focused coping strategies is favorable in terms of positive affect, which is parallel with the literature, that can be appraised as a strength of this study.

3.4.2. Negative Affect

The results of hierarchical regression analysis demonstrated that having a psychological disorder was positively associated with negative affect. Moreover, adaptation to caregiving was negatively associated with negative affect. At the first step of hierarchical regression analysis, having a psychological disorder predicted increased negative affect scores of caregivers of children with autism spectrum disorder. Since increased negative affect is common to depression and anxiety (Gençöz, 2002), this association was an expected one.

Caregivers who are able to manage symptoms of autism spectrum disorder, treatment and education; form relationships with health-care providers; who can maintain a positive self-image; and relate to family members and friends; manage their emotions; and prepare for future had lower negative affect scores. If the caregivers can adapt well to caregiving in terms of components of adaptation described above, it can be expected that their anxiety level would be decreased, since the level of anxiety was positively associated with appraisal of the situation as threatening and uncontrollable (Lazarus & Folkman, 1984). The decreased negative affect scores of caregivers, whose adaptation score was high, might be a result of this decreased anxiety, since anxiety and negative affect was significantly and positively associated (Gençöz, 2002).

Although an association between negative affect and perceived social support was expected, this association has not been demonstrated in this study. According to a study of Stuart and McGrew (2009), when social support increases, caregivers' burden decreases; thereby, caregivers experience less negative affect. However, it was suggested that with the increase of negative affect, the positive effects of social support on stress decreases (Çivitci, 2015). Therefore, because of increased negative affect, caregivers may not benefit from the stress-buffering effect of social support, even if they receive adequate social support.

3.4.3. Depression

The results of hierarchical regression analysis demonstrated that psychological disorder was positively associated with depression. Moreover, the age of children, perceived social support, adaptation to caregiving, and problem-focused coping were negatively associated with depression

As noted above, the association between depression scores and psychological disorder is highly predictable. Likewise, the association between depression scores and perceived social support has been demonstrated by different studies. For instance, according to a study by Falk et al. (2014), both maternal and paternal depression and stress were negatively correlated with social support. On the other hand, although it was suggested that longer caregiving duration did not affect depression levels of the caregivers of children with autism (Barker et al., 2011), hierarchical regression analysis revealed a different result, i.e., as the age of the child with autism spectrum disorder increased, the depression levels of caregivers decreased, as well. The decrease in depression scores was similar to what has been suggested for anxiety in Barker et al.'s study (2011). The decrease in depression levels may be explained by adaptation to caregiving tasks with the increase in experience or decreased expectations of caregivers, which in turn, may result in decreased disappointments, and less depressive symptoms.

After controlling for the effects of causal antecedents (i.e., age of children, perceived social support) adaptation to caregiving was also positively associated with depression. Caregivers, who can manage symptoms of autism spectrum disorder, treatment and education, their emotions related to autism spectrum diagnosis of their child, as well as who can form relationships with health-care providers and maintain a positive self-image, relate to family members and friends, and who are able to prepare for future, did report lower depressive symptoms in this study. As in the regression analyses where positive and negative affect were dependent variables, adaptation to caregiving is one of the key predictors of depression. Again, the caregivers, who can adapt to changes that occur after the diagnosis, can cope better with the negative aspects of caregiving, which in turn, may result in lower levels of depression.

As consistent with the literature (Benson, 2010; Pozo, Sarriá, & Brioso, 2013), problem-focused coping was negatively associated with depression, after controlling for the effects of causal antecedents. Caregivers who utilize more problem-focused coping reported less depressive symptoms in this study. Moreover, as discussed above, increase in problem-focused coping means higher levels of family adaptability (Lin, Orsmond, Coster, & Cohn, 2011). Therefore, the association between problem-focused coping, adaptation and depression can be related to each other.

Although a negative association between family income and level of depression was expected (Athari, Ghaedi, & Mohd Kosnin, 2013), this association was not demonstrated in this study. Since more than half of the participant caregivers (77.8 %) were the members of middle SES, the association of family income with caregiver depression can be examined more reliably with a study that has equivalently distributed participants in terms of SES.

3.4.4. Caregiver Well-Being

According to the results of hierarchical regression analyses, having someone to support for caregiving, perceived social support, and adaptation to caregiving were positively associated with basic needs. Moreover, the results of hierarchical regression analyses demonstrated that while having a psychological disorder was negatively associated with activities of living, child's behaviors related to autism spectrum disorder, perceived social support, age of the caregiver, and adaptation to caregiving was positively associated with activities of living.

It was highly predictable that having someone to support for caregiving is positively associated with basic need subscale of CWB Scale, since basic need subscale have questions with regard to the physical needs like sleep and nutrition, and some other needs such as personal growth, relaxation and expression of feelings. Having someone to support for caregiving might mean increased time and energy for caregivers of children with autism spectrum disorder to meet these needs, which explains this association.

Likewise, after the controlling for the effect of having someone to support for caregiving, perceived social support was still positively associated with both subscales of CWB scale, i.e., basic needs and activities of living. Having adequate social support and perceiving it as such mean increased family functioning (Manning, Wainwright, & Bennett, 2010) and family quality of life (Pozo, Sarriá, & Brioso, 2013), which may explain the increased scores of basic needs and daily functioning. As a result of increased social support, caregivers of children with autism spectrum disorder can satisfy their physical needs like sleep and nutrition, and some other needs like personal growth, relaxation, and adequate expression of feelings as well as increase their activities of living including the daily routine activities, and some leisure activities like having a hobby.

With the increase in age of the child with autism spectrum disorder, caregivers had increased activities of living scores. With this increase, which also means increase in caregiving duration, caregivers can be more experienced in terms of coping with adverse affects of caregiving and can adapt to changes related to their children's diagnosis. Child's behaviors related to autism spectrum disorder were positively associated with activities of living subscale, but not with basic needs subscale. Although it was revealed that with the increase in the severity of symptoms of autism spectrum disorder and the behavioral problems, individual and family burden (Stuart & Mcgrew, 2009) and caregiver stress (Lecavalier, Leone, & Wiltz, 2006; Lovell, Moos, & Wetherell, 2013) are also increased; and family quality of life (Pozo, Sarriá, & Brioso, 2013) is decreased, the results of hierarchical regression analysis showed an opposite association. Although this association may seem as inexplicable, with the increase in symptom severity, the caregivers might decrease their expectations of their children, which may result in decreased time for educating their children and increased activities of living scores.

Lastly, after controlling for the effects of causal antecedents, like all of the dependent variables of this study, adaptation to caregiving was also positively associated with both subscales of the CWB Scale. Caregivers who could manage symptoms of autism spectrum disorder, manage treatment and education, form relationships with health-care providers, manage their emotions related to autism spectrum diagnosis of their child, maintain a positive self-image, relate to family members and friends, and get prepared for future, did get higher basic needs and activities of living scores. Although changes after the diagnosis are almost same for all of the caregivers, well-being of caregivers are predicted by how well the caregivers adapt to these changes. Therefore, adaptation to caregiving becomes prominent as a key factor for depression, positive and negative affect, and well-being of caregivers of children with autism spectrum disorder. In order to decrease adverse affects of caregiving, the interventions should be designed to increase adaptation for changes in caregivers' life after the diagnosis.

3.4.5. Limitations

Although there are several strengths of this study as mentioned above, it is important to note some of its limitations, too. First of all, subgroups had unequal number of participants in the group comparisons. Therefore, the results of these analyses should be interpreted carefully. There were more mother caregivers than fathers (81.9 % vs. 18.1 %), most of the participants were members of middle SES (77.8 %), most of them were married (83.3 %), most of them had a high school or a higher degree (69.4%), most of the caregivers did not have a physical illness (84.7 %) or a psychological disorder (81.9), and most of them had more than one child (66.7 %). Therefore, the results of the study should be replicated with further studies conducted with participants that are distributed equivalently across the levels of variables.

Furthermore, although integrative coping model includes cognitive appraisal, it was not used as a variable in this study. The effects of cognitive appraisal on depression, positive affect, negative affect and well-being of caregiver is most probably important, since it has been claimed that the problem-focused coping should be preferred in the case of high-appraised control, and emotion-focused coping should be preferred in the case of low-appraised control (Folkman & Moskowitz, 2004). Therefore, it is important to include stress appraisal in further studies in order to get more reliable results.

The expected effects of both problem-focused coping and emotion-focused coping have not been demonstrated at the Study 2 of this thesis. While problem-focused coping was associated with the positive affect and depression, emotion-focused coping has not been associated with any of the dependent variables. On the other hand, adaptation to caregiving emerged as a key contributor to depression, positive and negative affect, and well-being. It is important to replicate the results of this study, since the situation specific coping strategies has been deemed to be significantly associated to depression, positive and negative affect, and well-being by many studies.

Lastly, although anxiety of caregivers emerged as an important variable in the qualitative part of this study, anxiety was not taken into account as an outcome variable in the Study 2. However, it might be important to understand the mechanisms that predict anxiety, as well as the association between anxiety and adaptation to caregiving and coping mechanisms. Therefore, not including anxiety as an outcome variable of Study 2 can be considered as a limitation of this thesis.

CHAPTER 4

STUDY 3: THE EFFECTIVENESS OF A COGNITIVE-BEHAVIORAL GROUP INTERVENTION FOR THE CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

4.1. Introduction: Interventions

There are several interventions designed to decrease stress, depression and anxiety levels of caregivers of children with autism spectrum disorder as well as to increase their subjective well-being and quality of life. Since increment in positive feelings (Shu, 2009) and effective coping strategies (McMillan et al., 2006 retrieved from Lovell & Wetherell, 2015) means improvement in the quality of life of caregivers and decrement in behavioral problems of children with autism spectrum disorder, some of the interventions target these feelings and coping strategies. The results of the cognitive-behavioral intervention program conducted with 17 mothers of children with Autism Spectrum Disorder showed that there is a significant decrease in terms of caregiver depression, burden, and negative mood state after participation to this intervention program. In this intervention, Ruiz-Roblediollo and Moya-Albiol (2015) taught caregiver's effective communication styles and assertiveness training as well as effective coping strategies. In another intervention program again conducted by Robleddillo et al. (2014) mindfulness-based interventions were used. They mainly focused on acceptance, reframing, and effective coping strategies to reduce health complaints and mood disturbances of the caregivers. In this study, caregivers of children with autism spectrum disorder were compared with caregivers of typically developed children. At the end of group sessions of nine weeks, although the caregivers of children with autism spectrum disorder showed greater improvements, both groups showed significant improvements in terms of mood, depression and anxiety levels, somatic symptoms, and self-perceived general health. Mindfulness-based interventions were also effective on positive reappraisal, feelings of well-being, and positive emotional states. Furthermore, anxiety, depression and stress scores were also decreased at the end of interventions (Rayan & Ahmad, 2016).

Another type of interventions was psychoeducational ones. The psychoeducational intervention developed by Patra et al. (2015) used semi-structured interviews to analyze problems of caregivers to develop an intervention program based on these needs. At the end of the intervention program, it was shown that stress levels of caregivers were decreased and their knowledge about autism was increased, which may also reduce caregiver burden (Zima, Kokot, & Rymaszewska, 2011).

Furthermore, the interventions those aim to enhance social support, rational thinking and positive reframing were also effective on well-being of caregivers of children with autism spectrum disorder. The interventions designed to support social relationships (Alquraini & Mahoney, 2015), familial and personal social activities (Phelps, Mccammon, Wuensch, & Golden, 2009) can decrease stress levels of autism caregivers. Moreover, caregivers of children with Autism Spectrum Disorder had a tendency to have more negative cognitions about their children's situation (Bekhet, 2016; Stuart & Mcgrew, 2009; Bekhet, Johnson, & Zauszniewski, 2012), more irrational beliefs and automatic negative thoughts (Predescu & Şipoş, 2013). These negative cognitions may result in increased caregiver burden, depression, anxiety and stress as well as more challenging behaviors of the child with autism. On the other hand, as a result of reframing the autism spectrum disorder diagnosis, parents can view the caregiving of a child with autism from a more positive perspective (Manning, Wainwright, & Bennett, 2010). Therefore, it can be suggested that the interventions that aim to change cognitions and coping strategies of caregivers, may educate them about autism spectrum disorder. These interventions can facilitate social activities and social support for caregivers, and thereby, help them to cope with negative outcomes of caregiving process and increase their well-being and positive emotions, which are positively correlated with quality of life of caregiver of children with autism spectrum disorder (Shu, 2009)

The aims of the Study 3 of this thesis were to develop an intervention program based on the data obtained from Study 1, and conduct this intervention with caregivers of children with autism spectrum disorder. It was hypothesized that at the end of the interventions, There will be statistically significant

1- Decrease in depressive symptoms of caregivers.
2- Decrease in negative affect scores of caregivers
3- Increase in positive affect scores of caregivers
4- Increase in activities of living scores of caregivers
5- Increase in basic needs scores of caregivers.

The intervention study was conducted as a 7-week group sessions with the caregivers of children with autism spectrum disorder.

4.2 Method

4.2.1. Participants

Six participants, all of whom were the mothers of children with autism spectrum disorder, participated in the intervention program. These six participants were not the same caregivers who participated in Study 1. The age of participants ranged between 32 and 44 (mean age = 37.33, *SD* = 5.43). All participants were married. While 4 of them identified themselves as a member of the middle-income group (66 %), one of them identified herself as a member of the lower-income group (16.50 %), and one of them as the higher-income group (16.50 %). Two of the participants were university graduates (33 %), 3 of them were high school graduates (50 %), and one participant had no formal education.

All participants’ children have been diagnosed with autism spectrum disorder. The time passed since their diagnosis with Autism Spectrum diagnose ranged between 6 months and 9 years with a mean of 4.25 years. The age of the children ranged between 3 years and 12 years (*M* = 6.67, *SD* = 3.72).

4.2.2. Measures

4.2.2.1. Beck Depression Inventory (BDI)

BDI (Beck, Rush, Shaw, & Emery, 1979) was used before and after the intervention program to measure changes in depression levels after the intervention. There are 21 multiple-choice questions in BDI, and the scores obtained from each item ranges between 0 and 3. Higher overall score from BDI (of 63) reflects a greater level of depression. BDI was adapted to Turkish by Hisli (1988), and test-retest reliability of the BDI for the Turkish version was .65, whereas the split-half reliability was .61 for depressive patients and .78 for students. By looking at BDI's correlation with Hamilton Depression Rating Scale (Hamilton, 1960), convergent validity of the scale was calculated as .75 (Hisli, 1988; 1989). The internal consistency reliability as measured by Cronbach's alpha was .89 for the present sample.

4.2.2.2. The Caregiver Well-Being Scale (CWB Scale)

In order to measure the changes in the well-being of caregivers after receiving the intervention, the Caregiver Well-Being Scale developed by Tebb (1995) have been employed. This scale consists of two subscales, namely basic needs and activities of living. The basic needs subscale includes the physical needs like sleep and nutrition and some other needs like personal growth, relaxation and expression of feelings. The internal consistency reliability of this subscale was .91(Berg-Weger, Rubio, & Tebb, 2000). The second subscale, which is activities of living, includes the daily activities and some additional leisure activities like having a hobby. The internal consistency reliability of the activities of living subscale as measured by Cronbach's alpha was .81. The correlation coefficient between the two subscales was found as .69, indicating the convergent validity of the subscales (Berg-Weger, Rubio, & Tebb, 2000). The Caregiver Well-Being Scale was adapted to Turkish by Demirtepe and Bozo (2009). Internal consistency reliability coefficients were .89 for the activities of living subscale and .93 for the basic needs subscale. Test-retest reliability of this scale was also strong (r = .79, p < .001). Caregiver Well Being Scale's divergent validity was assessed by its correlation with BDI (r = -.71, p < .01); and its convergent validity was assessed by its correlation by Mental, Physical and Spiritual Well-being Scale (MPSWS) (r = .55, p < .01) (Demirtepe & Bozo 2009). The internal consistency reliability as measured by Cronbach's alpha were .93 for basic needs subscale and .89 for activities of living subscale for the present sample.

4.2.2.3. Positive and Negative Affect Schedule

PANAS was used before and after the intervention program in order to measure changes in positive and negative affect after the intervention. It was developed by Watson, Clark, and Tellegen (1988) and PANAS has 20 items and two subscales. The first subscale is positive affect, which consists of 10 items, and the second subscale negative affect also consists of 10 items. The PANAS was adapted to Turkish by Gençöz (2000). In this scale, respondents rate their affective states in the last two weeks. Cronbach's alpha coefficient for positive affect was reported as .83 and for negative affect it was reported as .86. Test-retest reliability for Turkish version was .40 and .54 for positive and negative affect, respectively. Positive affect’s validity was assessed by its correlation with BDI ($r = -.48$, $p < .001$), and Beck Anxiety Inventory ($r = -.22$, $p < .005$). Moreover, negative affect’s validity was also assessed by its correlation with BDI ($r = .51$, $p < .001$) and Beck Anxiety Inventory ($r = .47$, $p < .001$) (Gencoz, 2000). The internal consistency reliabilities as measured by Cronbach's alpha were .87 for positive affect and .86 for negative affect in the present study.

4.2.3. Procedure: Caregiver Intervention Program

The intervention program developed for this thesis, caregiver support program, aimed to assist and support caregivers of children with autism spectrum disorder. It has been designed to promote self-care of caregivers, to provide an environment that caregivers can share and express their emotions related to their child's disorder, to educate and adequately inform the caregivers about autism spectrum disorder, to decrease their dysfunctional thoughts and cognitive distortions, and finally to increase more active use of problem-focused coping strategies. The intervention group was held in regular meetings, once a week on Saturdays, by the main researcher, and every meeting lasted approximately 2 hours. The meetings took place at the psychologist's office in a special education and rehabilitation center. At the end of the intervention program in post-test administration of the scales, it was expected that as compared to their pre-test scores, the caregivers will have higher scores in positive affect subscale of PANAS, in both subscales of the Caregiver Well-Being Scale, and lower scores on Beck Depression Inventory and negative affect subscale of PANAS.

The intervention program was designed according to the themes determined via the need assessment carried out in the first study of this thesis. In addition to the themes emerged in the first study, the intervention program developed in this study was based on the following books; *Cognitive*

Behavioral Therapy of Judith Beck (2011), *Stress, Appraisal and Coping* of Lazarus and Folkman (1984), *Feeling Good: The New Mood Therapy* of David Burns (1980) and *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (2013), as well as some of the articles that are cited in this thesis.

There were seven modules in caregiver support group, and each module was implemented in one session carried out once a week. The first module of the caregiver support group was psychoeducation. In this module, participants were informed about autism spectrum disorder including its etiology and symptoms. The second module aimed to educate participants about cognitive distortions, dysfunctional thoughts and how behaviors, cognitions, and emotions affect and affected by each other. Furthermore, participants' negative feelings related to their child's autism spectrum disorder diagnosis were also been identified and discussed.

The third module of the intervention program focused on the negative emotions; and their relation to cognitive distortions were examined and challenged with rational thoughts related to their children's autism spectrum disorder diagnosis. The fourth module was coping with stress. During this module, participants were informed about the symptoms of stress and functional and dysfunctional coping strategies. The fifth module was reserved for the discussion of the importance of social support. Throughout this module, participants were informed about the importance of social support on caregiver well-being and quality of life, as well as ways of asking for and accepting help and increasing social network. The sixth module was entitled as future. Accordingly, the aim of this module was to inform the participants about what the future holds for their children with autism spectrum disorder. Moreover, topics such as how to get prepared for future, accepting limitations, and legal rights of children with autism spectrum disorder were discussed. Each of the six modules was ended with progressive muscle relaxation. The questionnaires were given to participants at the last meeting of the intervention program. After the completion of the questionnaires by participants, previous weeks were evaluated with the participants and their feedbacks were received.

4.2.4. Data Analysis

Obtained data were analyzed using Wilcoxon signed-rank test. The reason of using this analysis was that it does not assumes normality in the data, since there were only 6 participants in the sample and normality in the data has been violated.

4.3. Results

The Wilcoxon signed-rank test showed that caregiver support program did lead to a statistically significant change in positive affect scores and both of the subscales of caregiver well being scale. On the other hand, caregiver intervention program did not elicit a statistically significant change in negative affect and depression scores.

After the 7-week intervention program, participants' positive affect scores of PANAS were significantly increased ($Z = -2.214$, $p = 0.027$). Median positive affect score rating was 28.0 in pre-test and 35.5 in post-test. Similarly, activities of living subscale scores of Caregiver Well-Being Scale were significantly increased at the end of interventions ($Z = -2.201$, $p = 0.028$). Median activities of living score rating was 64.5 in pre-test and 73.5 in post-test. Likewise, basic needs subscale scores of Caregiver Well-Being Scale were significantly increased at the end of interventions ($Z = -2.201$, $p = 0.028$). Median Basic Need score rating was 67.5 in pre-test and 75.0 in post-test.

At the end of the intervention program, although depression scores of participants were decreased, these changes were not statistically significant ($Z = -1.483$, $p = 0.138$). Median depression score rating was 16.0 in pre-test and 11.5 in post-test. Moreover, negative affect scores of participants obtained through PANAS administration did not significantly decrease at the end the intervention program (Z = -.667, p = 0.498). Median negative affect score rating was 18.0 in pre-test and 17.5 in post-test.

Thus, although the caregiver support program increased the caregivers' scores on positive outcome variables (i.e., activities of living, basic needs, and positive affect), it did not decrease their scores on negative outcome variables (i.e., depressive symptoms and negative affect).

4.4 Discussion

The “Caregiver Intervention Program” was developed and designed according to the findings obtained in the need assessment of caregivers of children with autism spectrum disorder in Study 1. Throughout the intervention program, mostly cognitive-behavioral therapy techniques were used. Besides cognitive behavioral therapy approach, psychoeducation about autism spectrum disorder, coping with stress, and importance of social support were also the modules of “Caregiver Intervention Program”. The seven-week intervention program provided an environment to caregivers to express and share their emotions, as well as to increase their effective coping strategies and social support.

As it was hypothesized, at the end of the seven-week intervention program, positive affect scores obtained through PANAS, and basic need and activities of living scores obtained through Caregiver Well Being Scale did significantly increase. However, both negative affect scores obtained through PANAS and depressive symptoms scores obtained through BDI did not significantly decrease.

The result of the “Caregiver Intervention program showed that there was a significant increase in terms of positive affect scores of caregivers. In other words, participants expressed significantly more positive emotions related to their last two weeks at the end of seven-week intervention program.

This result is consistent with the study of Rayan and Ahmad (2016), in which there was a significant increase in terms of positive emotional state after the caregiver intervention program. This change in positive affect can be explained by equity theory (Hatfield, Walster & Berscheid, 1978). According to this theory, the imbalance of taking and giving results in more distress. With the encouragement of asking and accepting social support during intervention program, participants might get increased social support. Therefore, participant caregivers might felt themselves as less distressed, which can explain their increased positive affect scores. Moreover, participant caregivers were encouraged to share their emotions related to their child's autism spectrum disorder and reappraise their situation with more rational thoughts, which could also increase their positive affect (Brans, Koval, Verduyn, Lim, & Kuppens, 2013).

Similar to the findings in the literature (e.g., Rayan, Ahmad, 2016), the well-being scores of participant caregivers were increased after the seven-week intervention program. Both basic needs and activities of living scores of Caregiver Well-Being Scale were significantly increased. Increased scores on the basic need subscale of Caregiver Well-Being Scale indicates that participant caregivers better fulfilled their basic needs like healthy nutrition and sleeping, as well as relaxation and expression of feelings. Our findings also indicated that the caregivers began to perform or increased daily activities and leisure activities at the end of interventions. At the "caregiver intervention program" caregivers encouraged to take care of themselves, use problem-focused coping strategies, ask and accept social support, use more rational way of thinking, and express their emotions. This significant increase in well-being scores can be explained by the different components of the interventions. As a result of using more problem focused coping strategies rather than emotion focused ones, the well being score of caregivers of child with autism spectrum disorder was increased at the end of both Benson's study (2010) and Pozo et al.'s study (2013). Furthermore, as in the findings regarding to positive affect, well-being is positively correlated with social support (Pozo, Sarriá, & Brioso, 2013), which may also explain these differences in well-being.

Although the hypotheses about well-being (i.e., basic needs and activities of living) and positive affect were confirmed with the Wilcoxon signed-rank test results, changes in negative affect and depression scores of caregivers did not significantly differ at the end of the intervention.

Since both negative affect and depressive symptoms of the caregivers were significantly and negatively correlated at the hierarchical regression analysis of Study 2, the insignificant change in negative affect and depressive symptoms may be related to caregivers adaptation to caregiving. Therefore, a module that supports caregivers in terms adaptation to caregiving might decrease negative affect and depressive symptoms, as well.

The insignificant decrease in depressive symptoms can be explained by some other perspectives, as well. Athari et al. (2013) suggested that while family income is negatively correlated with the level of depression, child's symptom severity is positively correlated. Moreover, according to study of Falk et al. (2014), child's aggressive behavior increases maternal depression. These factors might be more effective on caregiver depression than coping strategies, rational thinking style or social support, and accordingly, the insignificant changes in depression scores can be appraised as the result of child's symptom severity, child's aggressive behaviors, and family income.

In order to understand this statistically insignificant change in negative affect and depressive symptom scores, cultural backgrounds of participants should also be taken into account. According to study of Hofstede (1980), Turkey is a collectivistic society, in which people are expected to share fewer emotions (Singh-Manoux, Finkenauer, 2001) and suppress their emotions (Huwaë & Schaafsma, 2016). The insignificant change in negative affect and depressive symptom scores can be interpreted as stemming from this cultural framework. Thus, negative affect and depressive symptom scores obtained before the start of the intervention can be less than actual negative affect and depression levels of the participants. At the intervention program, caregivers were encouraged to talk about their emotions, gave feedback to each other, and share their emotions with their family and friends. For this reason, participant caregivers might have expressed their emotions more easily at post-test administration of the measures. For instance, one participant caregiver's negative affect score, can be interpreted in that perspective. Although the minimum negative affect score of PANAS can be 10, which interpreted as no negative affect, the negative affect score of this caregiver was 11 at pre-test and 17 at post-test. Likewise, the only increase in BDI score was 7 from 3 out of 63. Rather than explaining these changes as an increase in negative affect and depressive symptom level, it may be more appropriate to explain this difference as an increase in emotional sharing.

4.4.1. Implications

Although there is an increasing trend in autism spectrum disorder prevalence according to Centers for Disease Control and Prevention (2014), effects of this disorder on caregivers and how to prevent these adverse effects were not studied enough, especially in Turkey. Moreover, according to Ministry of Education of Turkey (Özel Eğitim ve Rehabilitasyon Merkezleri Yönetmeliği, 2011), every special education and rehabilitation center in Turkey, where children with autism spectrum disorder get education, must employ a full-time psychologist. When working with children with autism spectrum disorder, it is important to work also with caregivers, since caregiver depression and anxiety can explain child's comorbid depression and anxiety (Mazefsky, Conner, & Oswald, 2010). Therefore, interventions aiming to decrease caregiver depression and anxiety are also effective on child's depression and anxiety.

In order to help caregivers, the findings of the Study 3 of this thesis can be a guideline to the psychologists who work in these special education and rehabilitation centers. Furthermore, the intervention of this study was developed according to a qualitative study, which was conducted with caregivers. Although generalizability is a potential problem, this intervention program was specifically designed for caregiver's of autism spectrum disorder.

4.4.2. Limitations

The intervention study (Study 3) of this thesis revealed important findings. While both of the well-being indicators' and positive affect scores of participant caregivers were significantly increased, depression and negative affect scores of participant caregivers were not significantly decreased at the end of interventions. Therefore, it is possible to interpret these results as "Caregiver Intervention Program" was significantly effective on the psychological well-being of caregivers. However, there are also several limitations of this study that must be noted.

The caregiver intervention program consisted of different modules, and it is not possible to express which module of intervention is effective on depression, positive affect or well-being. There might be some inefficient modules that can be eliminated in the "Caregiver Intervention Program".

Although it was planned to conduct "caregiver intervention program" with more participants, there were not enough interest from autism caregivers to this intervention study. Because of limited participants and their lack of interest, it was not possible to have a control group and follow-up measurements. Therefore, it was not possible to say whether the changes observed at the end of intervention were permanent or not.

Although having a control group in intervention studies were criticized as being unethical, not having a control group can be considered as a limitation of this study.

All of the participants were mothers of children with autism spectrum disorder. Therefore, the effectiveness of “Caregiver Intervention Program” is unknown for fathers of children with autism spectrum disorder.

Lastly, insignificant changes in negative affect and depression were interpreted by present researcher as caregivers’ being more emotionally expressive after participation to the intervention program. However, this interpretation should be evaluated carefully and demonstrated in further studies.

CHAPTER 5: CONCLUSION

With the increase in lifespan, increase in chronic illnesses, disabilities and disorders, more and more people need caregivers. The caregiving experience can be a great burden, and source of stress and depression. Therefore, it is important to conduct studies that are designed to examine caregiving experiences, ways of coping with stress, adaptation to caregiving, and well-being of caregivers. Accordingly, this thesis aimed to assess the needs of caregivers of children with autism spectrum disorder, develop and conduct an intervention designed for caregivers of children with autism spectrum disorder, as well as to understand the predictors of well-being, positive affect, negative affect, and depression of these caregivers.

The results of this study indicated that the well-being, the level of positive and negative affect, and depressive symptoms of autism spectrum disorder caregivers are significantly associated with adaptation to caregiving. Therefore, it is highly important to develop interventions aiming to improve managing symptoms of autism spectrum disorder, managing treatment and education, forming relationships with health-care providers, managing emotions, maintaining a positive self-image, relating to family members and friends, and getting prepared for an uncertain future. The results of this study revealed the importance of adaptation to caregiving, maybe more than coping strategies, demographic factors, and social support. Furthermore, the association of problem focused coping with positive affect and depression was still congruent with the literature. The caregivers who utilized more problem-focused coping strategies had increased positive affect and lower levels of depression. Therefore, the result of this study also supported the interventions that aim to enhance problem-focused coping strategies.

The results of the qualitative study of this thesis indicated that the caregivers of children with autism spectrum disorder did not have sufficient knowledge about autism spectrum disorder, did not perceive sufficient social support, and were sad because of this disorder, and they were anxious about their children’s future, as well. These findings helped us to understand the impacts of this diagnosis on caregivers, and so, helped us to design an intervention program specific to these caregivers.

Although it is not known for sure which module(s) of the intervention was really effective, the “caregiver intervention program” of this study yielded an increased well-being and positive affect scores in caregivers of children with autism spectrum disorder. Therefore, it can be encouraged to apply this intervention on caregivers of children with autism spectrum disorder, and maybe with small variations on other caregivers.

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APPENDICES

APPENDIX A: INTERVIEW FORM

1. Hangi belirtiler üzerine çocuğunuzu doktora götürdünüz? Çocuğunuzun otizm spektrum bozukluğu tanısını aldığında neler yaşadınız?

2. Çocuğunuz otizm spektrum bozukluğu tanısı aldığında neler hissettiniz? Tanı alma sürecinden bu yana hislerinizde ne gibi değişiklikler oldu? Şu anda nasıl hissediyorsunuz?

3. Çocuğunuzun gösterdiği belirtilerin siz ve aileniz üzerinde ne gibi etkileri oldu?

4. Şimdiye kadar Otizm Spektrum Bozukluğu ile ilgili hangi alanlarda bilgilendirildiniz? Bu bozukluk ile ilgili yeterli bilgiye sahip olduğunuzu düşünüyor musunuz? Otizm spektrum bozukluğu ile ilgili hangi alanlarda bilgi sahibi olmak isterdiniz?

5. Bu süreçte yaşadığınız zorluklar ile baş etmenize neler yardımcı oldu?

6. Çocuğunuzun aldığı eğitimin yeterli olduğunu düşünüyor musunuz? Eğitim süreçleri ile ilgili yeterince bilgilendirildiğinizi düşünüyor musunuz? Eğitim süreçleri ile ilgili ne gibi değişikliklerin size faydalı olacağını düşünüyorsunuz?

7. Sizce otizm tanısı almış bir çocuğu annesi olarak güçlü ve zayıf yanlarınız nelerdir?

8. Çocuğunuzun bakımı ile ilgili karşılaştığınız zorluklar nelerdir? Ailenizin diğer fertlerinden yeterli desteği gördüğünüzü düşünüyor musunuz? Nasıl olmasını isterdiniz?

9. Çocuğunuzu gelecekte nelerin beklediğini düşünüyorsunuz? Çocuğunuzun geleceği ile ilgili neler hissediyorsunuz?

APPENDIX B: DEMOGRAPHIC INFORMATION FORM

1. Yaşınız:

2. Cinsiyetiniz: Kadın : Erkek:

3. Eğitim Durumunuz: Eğitimim Yok: Sadece Okur-Yazarım: İlkokul: Ortaokul: Lise: Üniversite: Yüksek Lisans/Doktora:

3. Medeni Haliniz: Bekar: Evli: Boşanmış : Eşi vefat etmiş:

6. Aylık gelir düzeyiniz: Düşük: Orta: Yüksek:

7. Çocuğunuzun yaşı:

8. Çocuğunuzun otizm spektrum bozukluğu tanısı alma yaşı:

9. Otizm Spektrum Bozukluğu tanısı almış çocuğunuzla beraber toplam kaç çocuğunuz var?

10. Otizm Spektrum Bozukluğu tanısı almış çocuğunuzun bakımında size destek olan birileri var mı: Var: Yok:

Var ise kim(ler)?______________

9. Herhangi bir fiziksel rahatsızlığınız var mı: Var: Yok:

10. Fiziksel bir rahatsızlığınız için tedavi görüyor musunuz: Evet: Hayır:

9. Herhangi bir psikolojik rahatsızlığınız var mı: Var: Yok:

10. Psikolojik rahatsızlığınız için tedavi görüyor musunuz: Evet: Hayır:

APPENDIX C: BECK DEPRESSION INVENTORY

Aşağıda gruplar halinde bazı sorular yazılıdır. Her gruptaki cümleleri dikkatle okuyunuz. Bugün dahil, geçen hafta içinde kandinizi nasıl hissettiğinizi en iyi anlatan cümleyi seçiniz. Seçmiş olduğunuz cümlenin yanındaki numaranın üzerine (X) işareti koyunuz.

1. (a) Kendimi üzgün hissetmiyorum.
(b) Kendimi üzgün hissediyorum.
(c) Her zaman için üzgünüm ve kendimi bu duygudan kurtaramıyorum.
(d) Öylesine üzgün ve mutsuzum ki dayanamıyorum.

2. (a) Gelecekten umutsuz değilim.
(b) Geleceğe biraz umutsuz bakıyorum.
(c) Gelecekten beklediğim hiçbir sey yok.
(d) Benim için bir gelecek yok ve bu durum düzelmeyecek.

3. (a) Kendimi başarısız görmüyorum.
(b) Çevremdeki birçok kişiden daha fazla başarısızlıklarım oldu sayılır.
(c) Geriye dönüp baktığımda, çok fazla başarısızlığımın olduğunu görüyorum.
(d) Kendimi tümüyle başarısız bir insan olarak görüyorum.

4. (a) Her şeyden eskisi kadar zevk alabiliyorum.
(b) Her şeyden eskisi kadar zevk alamıyorum.
(c) Artık hiçbir şeyden gerçek bir zevk alamıyorum.
(d) Bana zevk veren hiçbir şey yok. Her şey çok sıkıcı.

5. (a) Kendimi suçlu hissetmiyorum.
(b) Arada bir kendimi suçlu hissettiğim oluyor.
(c) Kendimi çoğunlukla suçlu hissediyorum.
(d) Kendimi her an için suçlu hissediyorum.

6. (a) Cezalandırıldığımı düşünmüyorum.
(b) Bazı şeyler için cezalandırılabileceğimi hissediyorum.
(c) Cezalandırılmayı bekliyorum.
(d) Cezalandırıldığımı hissediyorum.

7. (a) Kendimden hoşnutum.
(b) Kendimden pek hoşnut değilim.
(c) Kendimden hiç hoşlanmıyorum.
(d) Kendimden nefret ediyorum.

8. (a) Kendimi diğer insanlardan daha kötü görmüyorum.
(b) Kendimi zayıflıklarım ve hatalarım için eleştiriyorum.
(c) Kendimi hatalarım için çoğu zaman suçluyorum.
(d) Her kötü olayda kendimi suçluyorum.

9. (a) Kendimi öldürmek gibi düşüncelerim yok.
(b) Bazen kendimi öldürmeyi düşünüyorum, fakat bunu yapmam.
(c) Kendimi öldürebilmeyi isterdim.
(d) Bir fırsatını bulsam kendimi öldürürdüm.

10. (a) Her zamankinden daha fazla ağladığımı sanmıyorum.
(b) Eskisine göre şu sıralarda daha fazla ağlıyorum.
(c) Şu sıralarda her an ağlıyorum.
(d) Eskiden ağlayabilirdim, ama şu sıralarda istesem de ağlayamıyorum.

11. (a) Her zamankinden daha sinirli değilim.
(b) Her zamankinden daha kolayca sinirleniyor ve kızıyorum.
(c) Çogu zaman sinirliyim.
(d) Eskiden sinirlendiğim şeylere bile artık sinirlenemiyorum.

12. (a) Diğer insanlara karşı ilgimi kaybetmedim.
(b) Eskisine göre insanlarla daha az ilgiliyim.
(c) Diğer insanlara karşı ilgimin çoğunu kaybettim.
(d) Diğer insanlara karşı hiç ilgim kalmadı.

13. (a) Kararlarımı eskisi kadar kolay ve rahat verebiliyorum.
(b) Şu sıralarda kararlarımı vermeyi erteliyorum.
(c) Kararlarımı vermekte oldukça güçlük çekiyorum.
(d) Artık hiç karar veremiyorum.

14. (a) Dış görünüşümün eskisinden daha kötü olduğunu sanmıyorum.
(b) Yaşlandığımı ve çekiciliğimi kaybettiğimi düşünüyor ve üzülüyorum.
(c) Dış görünüşümde artık değiştirilmesi mümkün olmayan olumsuz değişiklikler olduğunu hissediyorum.
(d) Çok çirkin olduğumu düşünüyorum.

15. (a) Eskisi kadar iyi çalışabiliyorum.
(b) Bir işe başlayabilmek için eskisine göre kendimi daha fazla zorlamam gerekiyor.
(c) Hangi iş olursa olsun, yapabilmek için kendimi çok zorluyorum.
(d) Hiçbir iş yapamıyorum.

16. (a) Eskisi kadar rahat uyuyabiliyorum.
(b) Şu sıralarda eskisi kadar rahat uyuyamıyorum.
(c) Eskisine göre 1 veya 2 saat erken uyanıyor ve tekrar uyumakta zorluk çekiyorum.
(d) Eskisine göre çok erken uyanıyor ve tekrar uyuyamıyorum.

17. (a) Eskisine kıyasla daha çabuk yorulduğumu sanmıyorum.
(b) Eskisinden daha çabuk yoruluyorum.
(c) Şu sıralarda neredeyse her şey beni yoruyor.
(d) Öyle yorgunum ki hiçbir şey yapamıyorum.

18. (a) İştahım eskisinden pek farklı degil.
(b) İştahım eskisi kadar iyi degil.
(c) Şu sıralarda iştahım epey kötü.
(d) Artık hiç iştahım yok.

19. (a) Son zamanlarda pek fazla kilo kaybettiğimi sanmıyorum.
(b) Son zamanlarda istemediğim halde üç kilodan fazla kaybettim.
(c) Son zamanlarda istemediğim halde beş kilodan fazla kaybettim.
(d) Son zamanlarda istemediğim halde yedi kilodan fazla kaybettim.
Daha az yemeye çalışarak kilo kaybetmeye çalışıyorum. Evet ( ) Hayır ( )

20. (a) Sağlığım beni pek endişelendirmiyor.
(b) Son zamanlarda agrı, sızı, mide bozukluğu, kabızlık gibi sorunlarım var.
(c) Ağrı, sızı gibi bu sıkıntılarım beni epey endişelendirdiği için başka şeyleri düşünmek zor geliyor.
(d) Bu tür sıkıntılarım beni öylesine endişelendiriyor ki, artık başka hiçbir şey düşünemiyorum.

21. (a) Son zamanlarda cinsel yaşantımda dikkatimi çeken bir şey yok.
(b) Eskisine oranla cinsel konularla daha az ilgileniyorum.
(c) Şu sıralarda cinsellikle pek ilgili değilim.
(d) Artık cinsellikle hiçbir ilgim kalmadı.

APPENDIX D: CAREGIVER WELL-BEING SCALE

Aşağıda bazı temel ihtiyaçlar sıralanmıştır. Her bir ihtiyaç için hayatınızın son 3 ayını düşünün. Bu süre içinde her bir ihtiyacın ne ölçüde karşılandığını belirtiniz. Aşağıda bulunan ölçeği kullanarak sizin için uygun sayıyı yuvarlak içine alınız.

1 hiçbir zaman
2 nadiren
3 ara sıra
4 sık sık
5 her zaman

1. Yeterli paraya sahip olmak	1	2	3	4	5
2. Dengeli beslenmek	**1**	**2**	**3**	**4**	**5**
3. Yeterince uyumak	1	2	3	4	5
4. Fiziksel sağlığınıza dikkat etmek (doktora, diş hekimine gitmek vs.)	**1**	**2**	**3**	**4**	**5**
5. Kendinize vakit ayırmak	1	2	3	4	5
6. Sevildiğini hissetmek	**1**	**2**	**3**	**4**	**5**
7. Sevginizi ifade etmek	1	2	3	4	5
8. Öfkenizi ifade etmek	**1**	**2**	**3**	**4**	**5**
9. Neşenizi ve keyfinizi ifade etmek	1	2	3	4	5
10. Üzüntünüzü ifade etmek	**1**	**2**	**3**	**4**	**5**
11. Cinsellikten keyif almak	1	2	3	4	5
12. Yeni beceriler öğrenmek	**1**	**2**	**3**	**4**	**5**
13. Kendini değerli hissetmek	1	2	3	4	5
14. Başkaları tarafından takdir edildiğini hissetmek	**1**	**2**	**3**	**4**	**5**
15. Ailenizden hoşnut olmak	1	2	3	4	5
16. Kendinizden hoşnut olmak	**1**	**2**	**3**	**4**	**5**
17. Gelecekle ilgili kendinizi güvende hissetmek	1	2	3	4	5
18. Yakın arkadaşlara sahip olmak	**1**	**2**	**3**	**4**	**5**
19. Bir eve sahip olmak	1	2	3	4	5
20. Gelecekle ilgili planlar yapmak	**1**	**2**	**3**	**4**	**5**
21. Sizi düşünen birilerinin olması	1	2	3	4	5
22. Hayatınızın bir anlamı olması	**1**	**2**	**3**	**4**	**5**

Aşağıda herbirimizin yaptığı ya da birilerinin bizim için yaptığı bazı yaşamsal faaliyetler sıralanmıştır. Her bir faaliyet için yaşamınızın son 3 ayını düşünün. Bu süre içinde, her bir faaliyetin ne derecede karşılandığını düşünüyorsunuz? Aşağıda bulunan ölçeği kullanarak sizin için uygun sayıyı yuvarlak içine alınız.

1 hiçbir zaman
2 nadiren
3 ara sıra
4 sık sık
5 her zaman

1.	Yiyecek satın almak	1	2	3	4	5
2.	**Yemek hazırlamak**	**1**	**2**	**3**	**4**	**5**
3.	Evi temizlemek	1	2	3	4	5
4.	Evin çekip çevirilmesiyle ilgilenmek	1	2	3	4	5
5.	**Ulaşım kolaylığına sahip olmak**	**1**	**2**	**3**	**4**	**5**
6.	Kıyafet alış verişi yapmak	1	2	3	4	5
7.	**Kıyafetleri yıkamak ve giydiklerine özen göstermek**	**1**	**2**	**3**	**4**	**5**
8.	Gevşemek/ rahatlamak	1	2	3	4	5
9.	**Egzersiz/spor yapmak**	**1**	**2**	**3**	**4**	**5**
10.	Bir hobiden keyif almak	1	2	3	4	5
11.	**Yeni bir ilgi alanı ya da hobi edinmek**	**1**	**2**	**3**	**4**	**5**
12.	Sosyal etkinliklere katılmak	1	2	3	4	5
13.	**Herhangi bir konu hakkında derinlemesine düşünmek için zaman ayırmak**	**1**	**2**	**3**	**4**	**5**
14.	Manevi ve ilham verici faaliyetlere zaman ayırmak	1	2	3	4	5
15.	**Çevredenizdeki güzelliklerinin farkına varmak**	**1**	**2**	**3**	**4**	**5**
16.	Arkadaşlar ya da aileden destek istemek	1	2	3	4	5
17.	**Arkadaşlar ya da aileden destek almak**	**1**	**2**	**3**	**4**	**5**
18.	Gülmek/ kahkaha atmak	1	2	3	4	5
19.	**Kendinize iyi davranmak veya kendinizi ödüllendirmek**	**1**	**2**	**3**	**4**	**5**
20.	Kariyerinize/ işinize devam etmek	1	2	3	4	5
21.	**Kişisel temizlik ve dış görünüşünüze zaman ayırmak**	**1**	**2**	**3**	**4**	**5**
22.	Aile ya da arkadaşlarla hoşça vakit geçirmek için zaman ayırmak	1	2	3	4	5

APPENDIX E: POSITIVE AND NEGATIVE AFFECT SCALE

Bu ölçek farklı duyguları tanımlayan bir takım sözcükler içermektedir. Son iki hafta nasıl hissettiğinizi düşünüp her maddeyi okuyun. Uygun cevabı her maddenin yanında ayrılan yere (puanları daire içine alarak) işaretleyin. Cevaplarınızı verirken aşağıdaki puanları kullanın.

1. Çok az veya hiç
2. Biraz
3. Ortalama
4. Oldukça
5. Çok fazla

1. İlgili_ 1 2 3 4 5
2. Sıkıntılı 1 2 3 4 5
3. Heyecanlı 1 2 3 4 5
4. Mutsuz 1 2 3 4 5
5. Güçlü 1 2 3 4 5
6. Suçlu 1 2 3 4 5
7. Ürkmüş 1 2 3 4 5
8. Düşmanca 1 2 3 4 5
9. Hevesli 1 2 3 4 5
10. Gururlu 1 2 3 4 5
11. Asabi 1 2 3 4 5
12. Uyanık 1 2 3 4 5
13. Utanmış 1 2 3 4 5
14. İlhamlı 1 2 3 4 5
(yaratıcı düşüncelerle dolu)

15. Sinirli 1 2 3 4 5
16. Kararlı 1 2 3 4 5
17. Dikkatli 1 2 3 4 5
18. Tedirgin 1 2 3 4 5
19. Aktif 1 2 3 4 5
20. Korkmuş 1 2 3 4 5

APPENDIX F: WAYS OF COPING INVENTORY

Aşağıda, verilen her cümleyi dikkatle okuyunuz. Çocuğunuzun bozukluğu ve buna bağlı ortaya çıkan sorunlarla başa çıkmak için, bu cümlelerde anlatılanları ne sıklıkla kullandığınızı size uygun gelen kutuyu (X) ile isaretleyiniz. Hiçbir cümleyi cevapsız bırakmamaya çalışınız. Her cümle ile ilgili yalnız bir cevap kategorisini isaretleyiniz.

	Hiç uygun değil	Pek uygun değil	Uygun	Oldukça uygun	Çok uygun
1. Aklımı kurcalayan şeylerden kurtulmak için değişik işlerle uğraşırım					
2. İyimser olmaya çalışırım					
3. Bazı seyleri büyütmemeye üzerinde durmamaya çalışırım					
4. Sakin kafayla düsünmeye ve öfkelenmemeye çalışırım					
5. Olayın değerlendirmesini yaparak en iyi kararı vermeye çalışırım					
6. Problemin kendiliğinden hallolacağına inanırım					
7. Ne olursa olsun kendime direnme ve mücadele etme gücü hissederim					
8. Kendime karsı hoşgörülü olmaya çalışırım					
9. Olanları unutmaya çalışırım					
10. Telaşımı belli etmemeye ve sakin olmaya çalışırım					
11. "Başa gelen çekilir" diye düşünürüm					
12. Problemin ciddiyetini anlamaya çalışırım					
13. Kendimi kapana sıkışmış gibi hissederim					
14. "Her işte bir hayır vardır" diye düşünürüm					
15. Dua ederek Allah'tan yardım dilerim					
16. Olanla yetinmeye çalışırım					
17. Olanları kafama takıp sürekli					

düşünmekten kendimi alamam					
18. Mutlaka bir yol bulabileceğime inanır, bu yolda uğraşırım					
19. Sanki bu bir sorun değilmiş gibi davranırım					
20. “İş olacağına varır” diye düşünürüm					
21. Neler olabileceğini düşünüp ona göre davranmaya çalışırım					
22. İşin içinden çıkamayınca “elimden bir sey gelmiyor” der, durumu olduğu gibi kabullenirim					
23. Her şeye yeniden başlayacak gücü bulurum.					
24. Problemin çözümü için adak adarım					
25. Olaylardan olumlu bir şey çıkarmaya çalışırım					
26. Alın yazısına ve bunun değişmeyeceğine inanırım					
27. Soruna birkaç farklı çözüm yolu ararım					
28. Başıma gelenlerin herkesin başına gelebilecek şeyler olduğuna inanırım					
29. “Olanları keşke değiştirebilseydim” derim					
30. “Her şeye rağmen elde ettiğim bir kazanç vardır” diye düşünürüm					
31. Gururumu koruyup güçlü görünmeye çalışırım					
32. Problemi adım adım çözmeye çalışırım					
33. Elimden hiçbir şeyin gelmeyeceğine inanırım					
34. Problemin çözümü için hocaya okunurum					
35. Her şeyin istediğim gibi olmayacağına inanırım					
36. Bu dertten kurtulayım diye					

fakir fukaraya sadaka veririm					
37. Ne yapılacağını planlayıp ona göre davranırım					
38. Mücadeleden vazgeçerim					
39. Sorunun benden kaynaklandığını düşünürüm					
40. Olaylar karşısında “kaderim buymuş” derim					
41. “Keşke daha güçlü bir insan olsaydım” diye düşünürüm					
42. Nazarlık takarak, muska taşıyarak benzer olayların olmaması için önlemler alırım					
43. Ne olup bittiğini anlayabilmek için sorunu enine boyuna düşünürüm					
44. “Benim suçum ne” diye düşünürüm					
45. “Allah’ın takdiri buymuş” diye kendimi teselli ederim					
46. Temkinli olmaya ve yanlış yapmamaya çalışırım					
47. Çözüm için kendim bir seyler yapmak istemem					
48. “Hep benim yüzümden oldu” diye düşünürüm					
49. Mutlu olmak için baska yollar ararım					
50. Hakkımı savunabileceğime inanırım					
51. Bir kişi olarak iyi yönde değistiğimi ve olgunlaştığımı hissederim					

APPENDIX G: MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT

Aşağıda 12 cümle ve her birinde de cevaplarınızı işaretlemeniz için 1 den 7ye kadar rakamlar verilmiştir. Her cümlede söyleneni 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.

1. İhtiyacım olduğunda yanımda olan özel bir insan var.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

2. Sevinç ve kederimi paylaşabileceğim özel bir insan var.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

3. Ailem bana gerçekten yardımcı olmaya çalışır.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

4. İhtiyacım olan duygusal yardımı ve desteği ailemden alırım.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

5. Beni gerçekten rahatlatan bir insan 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 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. Yaşamımda duygularıma önem veren özel bir insanım.

Kesinlikle hayır	1	2	3	4	5	6	7	Kesinlikle evet

11. Kararlarımı vermede ailem 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 H: GENERAL SELF-EFFICACY SCALE

Aşağıda 10 cümle vardır ve her cümlede söyleneni sizin için ne kadar doğru olduğunu veya olmadığını belirtmek için o cümle yanındaki boşluklardan yalnız bir tanesini işaretleyiniz. Bu şekilde 10 cümlenin her birinde bir işaret koyarak cevaplarınızı veriniz.

	Tamamen Doğru	Doğru	Yanlış	Tamamen Yanlış
1. Yeterince çaba harcarsam, zor sorunları çözmenin bir yolunu daima bulabilirim.				
2. Bana karşı çıkıldığında, istediğimi elde etmemi sağlayacak bir yol ve yöntem bulabilirim.				
3. Amaçlarıma bağlı kalmak ve bunları gerçekleştirmek benim için kolaydır.				
4. Beklenmedik olaylarla etkili bir biçimde başa çıkabileceğime inanıyorum.				
5. Yeteneklerim sayesinde beklenmedik durumlarla nasıl baş edebileceğimi biliyorum.				
6. Gerekli çabayı gösterirsem, birçok sorunu çözebilirim.				
7. Baş etme gücüme güvendiğim için zorluklarla karşılaştığımda, genellikle birkaç çözüm yolu bulabilirim.				
8. Bir sorunla karşılaştığımda, genellikle birkaç çözüm yolu bulabilirim.				
9. Başım dertte olduğunda, genellikle bir çözüm düşünebilirim.				
10. Önüme çıkan zorluk ne olursa olsun, üstesinden gelebilirim.				

APPENDIX I: AUTISM BEHAVIOUR CHECKLIST

Aşağıda otizm spektrum bozukluğu tanısına sahip çocukların sergilediği bazı davranışlar vardır. Çocuğunuzu sergilediği davranışlar için EVET, sergilemediği davranışlar için ise HAYIR seçeneğinin altındaki kutuya işaret koyunuz.			
		Evet	**Hayır**
1	Kendi etrafında uzun süre döner.		
2	Basit bir işi öğrenir ama çabuk unutur.		
3	Sosyal veya çevresel uyaranlara(sesler, ışık, insanlar, konuşma, seslenme gibi) sıklıkla cevap vermez.		
4	Basit emirleri bir kere söylendiğinde yerine getirmez.(otur, buraya gel, ayağa kalk gibi)		
5	Oyuncakları uygun şekilde kullanmaz.(Örneğin arabalarla normal oynamaz, ters çevirip tekerleklerini döndürerek seyreder.)		
6	Eşyaların ve oyuncakların büyüklüğüne, rengine, pozisyon gibi bir özelliğine takılır kalır, aşırı ilgilenir.		
7	Karşılıklı olarak gülümsemesi yoktur.(Kendi kendine veya anlamsız gülmeleri olabilir.)		
8	Zamirleri ters kullanır.(örneğin "ben" yerine "sen" der.)		
9	Bazı nesneleri bırakmak istemez, yanında taşımakta ısrar eder.		
10	İşitmiyor gibi görünebilir bu sebeple işitme kaybı olduğu kuskusunu uyandırır.		
11	Konuşması ritmik değildir, belli bir tonu yoktur.		
12	Kendi kendine uzun süreler sallanır.		
13	Ona doğru uzanıldığında kollarını uzatmaz.(bu durum bebeklik döneminde de olmuş olabilir.)		
14	Çevredeki veya günlük programındaki düzenin değişikliğine aşırı tepki verir.		
15	Başka insanların arasındayken, diğerlerinin isimleri ile beraber kendi ismi de söylendiğinde cevap vermez.		
16	Kendi etrafında dönme, parmak ucunda yürüme, kanat çırpma vs. gibi hareketleri vardır, bazen bu davranışlarını keserek birden bağırır ve ani hareketler yapar.		
17	Başka insanların yüz ifadelerine ve duygularına karşı cevapsızdır.		
18	"Evet" veya "ben" sözcüklerini nadiren kullanır.		
19	Gelişiminin bir alanında özel yetenekleri vardır, bu		

	genel zihinsel düzeyinin üzerindedir. Örnek veriniz.		
20	“Topu kutunun üstüne koy, topu kutunun içine koy” gibi yer bildiren emirleri uygulayamaz.		
21	Bazen yüksek ve ani seslere “irkilme” tepkisi vermez.		
22	Kanat çırpma gibi kendini uyarıcı davranışları vardır.		
23	Zaman zaman çok şiddetli öfke patlamaları veya çok sık küçük öfke nöbetleri geçirir.		
24	Göz göze gelmekten kaçınır.		
25	Dokunulmaya veya tutulmaya itiraz eder.		
26	Bazen çürük, kesik, iğne yapma gibi acı verici uyaranlara hiç tepki vermez.		
27	Şimdi veya bebekken gergin, kucakta tutulması zor bir bebektir.		
28	Kucağa alındığında pelte gibidir, sarılmaz tutunmaz.		
29	Belirli bir yüz ifadesi takınarak istediği eşyayı alır.		
30	Parmak uçlarında yürür.		
31	Isırarak, vurarak, tekmeleyerek diğerlerinin canını yakar.		
32	Bazı cümleleri defalarca tekrarlar.		
33	Oyun oynarken diğer çocukları taklit etmez.		
34	Gözlerine parlak bir ışık tutulduğunda genellikle gözlerini kırpmaz.		
35	Kafasını vurarak, elini ısırarak kendi canını acıtır.		
36	İhtiyaçlarının hemen karşılanmasını ister, bir süre bekleyemez.		
37	İsmi söylenen beş nesneden daha fazlasını işaret ederek gösteremez.		
38	Hiç arkadaşı yoktur.		
39	Bir çok sese kulaklarını kapatır.		
40	Eşyaları çevirir, döndürür, yere çarpar.		
41	Tuvalet eğitimi sorunludur.		
42	Çoğunlukla korkar ya da çok kaygılıdır(sıkıntılıdır)		
43	İsteklerini ve ihtiyaçlarını belirtmek için ya hiç konuşmaz ya da kendiliğinden söylediği kelime sayısı 5`i geçmez.		
44	Normal gün ışığında bile gözlerini kısar, kaşlarını çatar, gözlerini kapatır.		
45	Yardımsız kendisi giyinemez.		
46	Sesleri ve sözcükleri sık sık tekrar eder.		
47	Bakışları sanki insanı “delip geçermiş gibidir.		
48	Başkalarının sorularını veya sesli ifadelerini tekrarlar.		
49	Çevresinde olup bitenin sıklıkla farkında değildir ve		

	tehlikeli durumlarda ilgisiz kalabilir.		
50	İnsanlardan ziyade cansız nesnelerle oynamayı ve vakit geçirmeyi tercih eder.		
51	Eşyaların tadına bakar ,koklar, uzun süre dokunur.		
52	Ortamda yeni bir kişi bulunduğunda görsel tepki vermez, bakmaz, onunla ilgilenmez.		
53	Eşyaları sıraya dizmek gibi daha karmaşık törensi davranışları vardır.		
54	Çok zarar vericidir, oyuncaklarını ve ev eşyalarını hemen kırar.		
55	Gelişimsel gecikme belirtileri 30.ayda veya daha önce başlamıştır.		
56	Gün içinde kendiliğinden iletişim sağlamak için kullandığı kelime sayısı 15 ile 30 arasındadır.		
57	Uzun süreler boşluğa bakar.		

APPENDIX J: CAREGIVER ADAPTATION SCALE FOR AUTISM

Bu ölçek çocuğunuzun Otizm Spektrum Bozukluğu tanısı aldıktan sonra gerçekleşen değişikliklere ebeveyn olarak ne kadar uyum sağlayabildiğinizi ölçmektedir. Ölçekte bulunan her bir soruyu ayrı ayrı değerlendirip 1-Hiç Uygun Değil, 2-Pek Uygun Değil, 3-Biraz Uygun Değil, 4- Ne Uygun Ne Uygun Değil, 5-Biraz Uygun, 6-Uygun ve 7-Tamamen Uygun seçeneklerinden birini işaretlemeniz gerekmektedir.

	1-Hiç Uygun Değil	2-Pek Uygun Değil	3-Biraz Uygun Değil	4- Ne Uygun Ne Uygun Değil	5-Biraz Uygun	6-Uygun	7-Tamamen Uygun
1.Çocuğumun isteklerini anlayamıyorum							
2.Çocuğumun ihtiyaçlarını anlayabiliyorum							
3.Çocuğumun isteklerini karşılayabiliyorum							
4.Çocuğumun ihtiyaçlarını karşılayamıyorum							
5.Çocuğumun davranış problemi göstereceği zamanları önceden anlayabiliyorum							
6.Çocuğum ağladığında bunun sebebini anlayabiliyorum							
7.Çocuğum ağladığında bununla başa çıkamıyorum							
8.Çocuğum bağırdığında bunun sebebini anlayabiliyorum							
9.Çocuğum bağırdığında bununla başa çıkabiliyorum							
10.Çocuğum kendine şiddet gösterdiğinde bununla başa çıkabiliyorum							
11.Çocuğum kendine şiddet gösterdiğinde bunun sebebini							

anlayabiliyorum							
12.Çocuğum bana şiddet gösterdiğinde bununla başa çıkabiliyorum							
13.Çocuğum bir başkasına şiddet gösterdiğinde bununla başa çıkamıyorum							
14.Çocuğum bir başkasına şiddet gösterdiğinde bunun sebebini anlayabiliyorum							
15.Çocuğum bana şiddet gösterdiğinde bunun sebebini anlayamıyorum							
16. Çocuğumun (eğer alıyorsa) özel eğitim sürecine uyum sağlayamadım							
17.Çocuğumun (eğer alıyorsa) kaynaştırma eğitimine uyum sağlayamadım							
18.Çocuğumun (eğer alıyorsa) özel alt sınıf eğitimine uyum sağlayamadım							
19.Çocuğumun ihtiyacı olan eğitim için gerekli kaynaklara ulaşabiliyorum							
20.Çocuğumun daha iyi bir eğitim alması ile ilgili neler yapacağımı biliyorum							
21.Çocuğumun hangi alanlarda eğitime ihtiyaç duyduğunu anlayabiliyorum							
22.Doktor kontrollerine ve rapor alma-yenileme süreçlerine uyum sağlayamadım							
23.Doktor kontrollerinde ve rapor alma-							

yenileme süreçlerinde sağlık personeli ile istediğim gibi iletişim kurabiliyorum							
24.Çocuğumun öğretmeni ile istediğim gibi iletişim kurabiliyorum							
25.Çocuğumun öğretmenine isteklerimi ifade edemiyorum							
26.Çocuğumun psikoloğu ile istediğim gibi iletişim kurabiliyorum							
27.Çocuğumun psikoloğuna isteklerimi ifade edemiyorum							
28. Çocuğumun psikiyatristi ile istediğim gibi iletişim kuramıyorum							
29.Çocuğumun psikiyatristine isteklerimi ifade edebiliyorum							
30.Otizm spektrum bozukluğu tanısı almış bir çocuğun ebeveyni olarak olumsuz duyguların yarattığı etkileri kontrol edebiliyorum							
31.Otizm spektrum bozukluğu tanısı almış bir çocuğun ebeveyni olarak olumsuz duygularımla başa çıkamıyorum							
32.Otizm spektrum bozukluğu tanısı almış bir çocuğun ebeveyni olarak duygusal ihtiyaçlarımı karşılayamıyorum							
33.Kendi fiziksel bakımımı istediğim şekilde							

sağlayabiliyorum							
34.Kendime istediğim kadar vakit ayıramıyorum							
35.Kendi öz bakımımı istediğim şekilde sağlayabiliyorum							
36.Fiziksel sağlığıma dikkat edemiyorum							
37.Kendimden hoşnutum							
38.Dış görünüşüme özen gösterebiliyorum							
39.Kök ailem (kendi anne-babam ve kardeşlerim) ile ilişkilerimi sağlıklı bir şekilde sürdürebiliyorum							
40.Çekirdek ailem (eşim ve diğer çocuklarım) ile ilişkilerimi sağlıklı bir şekilde sürdürebiliyorum							
41.Çekirdek ailem (eşim ve diğer çocuklarım) ile yaşadığım problemleri sağlıklı bir şekilde çözebiliyorum							
42.Kök ailem (kendi anne-babam ve kardeşlerim) ile yaşadığım problemleri sağlıklı bir şekilde çözebiliyorum							
43.Kök ailemden (kendi anne-babam ve kardeşlerim) beklediğim desteği onlara ifade edebiliyorum							
44.Çekirdek ailemden (eşim ve diğer çocuklarım) beklediğim desteği onlara ifade edebiliyorum							
45.Çekirdek ailemden (eşim ve diğer çocuklarım)							

beklediğim desteği alamıyorum							
46.Kök ailemden (kendi anne-babam ve kardeşlerim) beklediğim desteği alamıyorum							
47.Arkadaşlarımla ilişkilerim sağlıklı bir şekilde sürdürebiliyorum							
48.Arkadaşlarımdan beklediğim desteği onlara ifade edebiliyorum							
49.Arkadaşlarımdan beklediğim desteği alabiliyorum							
50.Çocuğumun gelecekte karşılaşabileceği sağlık problemleri için gerekli hazırlığı yapabiliyorum							
51.Çocuğumun gelecekte alması gereken eğitim için gerekli hazırlığı yapabiliyorum							
52.Çocuğumun gelecekte karşılaşabileceği ekonomik zorluklar için gerekli hazırlığı yapabiliyorum							
53.Çocuğumun gelecekte ihtiyaç duyabileceği bakım için gerekli hazırlıkları yapabiliyorum							

APPENDIX K: TURKISH SUMMARY

OTİZM SPEKTRUM BOZUKLUĞU TANISI ALMIŞ ÇOCUKLARA BAKIM VEREN EBEVEYNLER: İHTİYAÇ ANALİZİ, MODEL TESTİ VE MÜDAHALE ÇALIŞMASI

1. Giriş

Bütün insanların çocukluk döneminde bakım almaya ihtiyaç duymasının yanında, kronik hastalığı bulunan kişiler, engelli bireyler ve gelişimsel bozukluğa sahip bireyler sürekli ya da uzun sureli bakım almaya ihtiyaç duymaktadırlar ve bu bakım çoğunluklar kişilerin aile bireyleri tarafından sağlanmaktadır. 2015 yılında Amerika Birleşik Devletlerinde yaklaşık 43.5 milyon para kazanmayan bakım veren bulunmaktadır ve bunların % 60'ı kadın, %85'i ise bakım alanın aile üyesidir (Caregiving in the U.S., 2015). Bakım verme bireyin zaman ve para gibi kaynaklarını tükettiğinden, çoğunlukla stres ve tükenmişlik kaynağıdır..

Nöro-gelişimsel bozukluğa sahip bir çok bireyde olduğu gibi, otizm spektrum bozukluğu tanısı almış çocuklar da çoğunlukla sürekli bakıma ihtiyaç duymaktadırlar (Ruiz-Robledillo & Moya-Albiol, 2015). Otizm spektrumun tanısı konma oranının yıldan yıla artması, bir taraftan da otizmli spektrum bozukluğu tanısı almış bireylere bakım verenlerin sayısının da artması anlamına gelmektedir. Otizm spektrum bozukluğu ortalama olarak her 68 yeni doğan çocuktan birine konmaktadır (Centers for Disease Control and Prevention, 2014). Otizm spektrum bozukluğu tanısına sahip çocuklar sosyal iletilişimde eksikliklere sahip olmakta, kısıtlı ve tekrar eden davranış motifleri ve ilgiler sergileyebilmektedirler.

Türkiye'de otizm spektrum bozukluğu tanısı almış bireyler genellikle kaynaştırma eğitimi, özel eğitim sınıflarında eğitim, otistik çocuklar eğitim merkezlerinde eğitim ya da otistik çocuklar iş eğitim merkezlerinde eğitim almaktadırlar. Otizmli çocuklar bu eğitimlerden yararlanabilmek için devlet hastanelerinden bir sağlık belgesi almalıdırlar ve bu sağlık belgesi sonucunda eğitim masrafları Milli Eğitim Bakanlığı tarafından sağlanmaktadır (Otizmli Bireylerin Hakları, 2013).

Tezin sonraki bölümünde otizm spektrum bozukluğu tanısı almış bireylere bakım verenlerin iyi olma durumları ve iyi olma durumlarını etkileyen değişkenler ile ilgili bilgi verilecektir.

1.1. Bakım Verme

1.1.1. Demografik Değişkenler

Bakım veren bireyin demografik özellikleri, bireyin yaşam kalitesi, stres, kaygı ve depresif semptom seviyesi üzerinde önemli bir etkiye sahip olabilmektedir.

Örneğin ailenin gelir seviyesinin bakım verenin depresyon ve stres seviyeleri ve çocuğun otizm spektrum bozukluğu semptomlarının çokluğu ile negatif yönde korale olduğu ortaya konmuştur (Athari, Ghaedi, & Mohd Kosnin, 2013). Buna ek olarak annenin yaşının annenin kaygı seviyesi ile negatif şekilde korale olduğu da yapılan çalışmalarda ortaya konan bir diğer bulgudur Falk, Norris, & Quinn, 2014; Barker et al., 2011).

1.1.2. Sosyal Destek

Sosyal destek bakım verenler için iyi bilinen bir koruyucu faktördür. Diğer koruyucu faktörler gibi, sosyal desteğin artması, bakım verenlerin iyi olma durumlarını farklı şekillerde olumlu etkilemektedir. Sosyal destek ile aile uyumu, aile fonksiyonelliği ve aile yaşam kalitesi arasında pozitif bir ilişki vardır. Diğer bir deyişle sosyal destek arttıkça aile uyumu Lin, Orsmond, Coster, & Cohn, 2011), aile fonksiyonelliği (Manning, Wainwright, & Bennett, 2010) ve aile yaşam kalitesi (Pozo, Sarriá, & Brioso, 2013) artmaktadır. Benzer bir şekilde Stuart ve McGrew’in çalışması (2009) göstermiştir ki bireysel ve aile tükenmişliği sosyal desteğin artmasıyla düşüşe geçmektedir. Dahası hem annelerin hem de babaların depresif semptomları ve stres seviyeleri sosyal destek ile negatif yönde ilişkili bulunmuştur (Falk, Norris, & Quinn, 2014).

1.1.3. Başa Çıkma

Bakım verenler tarafından kullanılan stresle başa çıkma yöntemleri, bakım veren iyi olma durumunu yordayan bir diğer değişkendir. Genel olarak problem odaklı başa çıkma yöntemleri bakım veren iyi olma durumunu olumlu yönde yordarken, duygusal başa çıkma yöntemleri olumsuz yönde yordamaktadır. Diğer bir taraftan uyum gösterilmesi gereken durum ile başa çıkma yönteminin de uyması gerekmektedir (Holahan & Moos, 2007). Bu anlamda bireylerin kontrollerini yüksek olarak yorumladıkları durumlarda problem odaklı başa çıkma yöntemlerinin, kontrollerini düşük olarak yorumladıkları durumlarda ise duygusal odaklı başa çıkma yöntemlerinin tercih edilmesi, bakım veren iyi olma durumu üzerinde olumlu etkilere sahip olabilecektir (Folkman & Moskowitz, 2004).

1.1.4. İyi Olma

Otizm spektrum bozukluğu tanısı almış bir çocuğa sahip olma ebeveynleri bir çok yönden etkileyen bir durumdur.

Otizm spektrum bozukluğu tanısı almış çocukların ebeveynleri diğer nörogelişimsel bozukluklar tanısı almış çocukların ebeveynleri , ile kıyaslandığında, otizm spektrum bozukluğu tanısının olumsuz etkileri kolaylıkla fark edilebilmektedir. Otizm spektrum bozukluğu tanısı almış çocukların ebeveynleri, Down sendromu tanısına sahip çocukların ebeveynlerine göre daha fazla tükenmişlik belirtileri göstermektedirler (Zima, Kokot, & Rymaszewska, 2011; Eisenhower, Baker, & Blacher, 2005). Benzer bir şekilde otizm spektrum bozukluğu tanısı almış çocukların ebeveynleri ile genel popülasyon karşılaştırıldığında, otizm spektrum bozukluğu tanısı almış çocukların ebeveynlerinin daha fazla kronik stres, (Ruiz- Robledillo & Moya-Albiol, 2015), depresyon semptomu (Manning, Wainwright, & Bennett, 2010) ve kaygı semptomu (Dabrowska & Pisula, 2010) gösterdikleri ve algılanan genel sağlıklarının daha düşük olduğu (Bouma & Schweitzer, 1990; Hayes & Watson, 2012) ortaya konmuştur..

1.2. Çalışmanın Amacı ve Önemi

Bu çalışmanın amacı otizm spektrum bozukluğu tanısına sahip çocukların bakım verenlerinin iyilik hallerini yordayan etmenleri incelemek ve bu bakım verenler için bir grup müdahale programı geliştirmektir. Bu tez birbiri ile ilişkili üç, ayrı çalışmadan oluşmaktadır. Bu çalışmalar (1) otizm spektrum bozukluğu birincil bakım verenlerinin problemlerini belirleme, (2) birincil bakım verenlerin iyilik hallerini yordayan etmenleri Holahan ve Moos'un (2007) entegre başa çıkma modeli çerçevesinde ortaya çıkarma ve (3) otizm spektrum bozukluğu birincil bakım verenlerine yönelik bir grup müdahale programı geliştirmek ve uygulamaktır.

2. Birinci Çalışma: Otizm Spektrum Bozukluğu Tanısı Almış Çocukların Ebeveynlerinin Bu Sürece Uyumlarının Nitel Analizi

Birinci çalışma otizm spektrum bozukluğu birincil bakım verenlerinin öznel deneyimlerini 6 katılımcı ile incelemiştir. Katılımcılar ile görüşmeler yüz yüze gerçekleştirilmiş, çalışmanın amacı ile ilgili bilgilendirilme sonrasında mülakatlar yapılmıştır. Mülakatlar esnasında katılımcıların iznine istinaden ses kaydı yapılmış, 2 katılımcının ses kaydı istememesi dolayısı ile görüşme sırasında notlar alınmıştır. Mülakatlar sırasında önceden belirlenmiş

9 soru katılımcılara sorulmuştur. Daha sonra ses kayıtları notlara geçirilmiş ve Braun ve Clarke' ın (2006) önerdiği şekilde tematik analiz gerçekleştirilmiştir. Bu çalışmada belirlenen temalar yetersiz bilgi, duygular, sosyal destek ve değişim'dir. Ortaya çıkan temaların literatür ile uyumludur.

Birinci çalışmada gerçekleştirilen nitel analizin amacı, ailelerin bakım verme süreçlerinde yaşadıkları sorunları belirlemektir. Üçüncü çalışmada gerçekleştirilen grup müdahale programı için önemli veriler ortaya koyan birinci çalışma, geliştirilen müdahale programının içeriğini büyük oranda belirlemiştir.

Verdiği önemli bilgilere rağmen gerçekleştirilen nitel analizin önemli sınırlılıkları da bulunmaktadır. İlk olarak katılımcı sayısının oldukça kısıtlı olması göze çarpmaktadır. Buna ek olarak mülakatların ve tematik analizin aynı araştırmacı tarafından gerçekleştirilmiş olması da diğer bir sınırlılık olarak göze çarpmaktadır.

3. İkinci Çalışma: Otizm Spektrum Bozukluğu Tanısı Almış Bireylere Bakım Verenlerin Depresyon, Olumlu Duygulanım, Olumsuz Duygulanım ve İyi Olma Hallerinin Yordayıcıları

72 katılımcı ile gerçekleştirilen ikinci çalışma Holahan ve Moos'un (2007) entegre başa çıkma modelini baz alarak depresyon, olumlu duygulanım, olumsuz duygulanım ve iyi olma hallerini yordayıcıları belirlemeyi amaçlamıştır.

Holahan ve Moos'un entegre başa çıkma modeli birbirleriyle ilişkili 7 panelden oluşmaktadır. Bu modele göre başa çıkma yöntemlerinin seçimi, sağlıkla ilgili faktörler, kişisel kaynaklar, fiziksel ve sosyal bağlam, bilişsel değerlendirme ve uyum gerektiren vazifelerle ilgilidir. Kişisel kaynaklar, sağlıkla ilgili faktörler ve sosyal ve fiziksel bağlam sağlıkla ilgili durumun nasıl değerlendirildiğini ve uyum gerektiren vazifelerin nasıl formüle edileceğini belirler.

Panel 1 kişisel kaynakları içerir. Kişisel kaynaklar entelektüel beceriyi, benlik gücünü, öz yeterliliği, yaş cinsiyet, eğitim gibi demografik faktörleri, kişilik faktörlerini ve problem çözme stillerini kapsar. Bu çalışmada Panel 1, demografik bilgi formu ve genel öz yeterlilik ölçeği aracılığı ile değerlendirilmiştir.

Panel 2 hastalık, bozukluk ya da engellilik durumunun gelişimini ve ilerleyişini, evresini ve tipini içeren sağlıkla ilgili faktörleri kapsamaktadır. Bu çalışmada Panel 2 Otizm Davranış Kontrol Listesi aracılığı ile ölçülmüştür.

Panel 3 sosyal ve fiziksel bağlamı kapsar. Sosyal ilişkiler ve sosyal destek sosyal bağlamı oluştururken, ev ya da işyerinin fiziksel özellikleri fiziksel bağlamı kapsar. Diğer taraftan panel 4, bilişsel değerlendirmeden oluşur ve bu panel problemin meydan okuma, veya tehdit, kontrol edilebilir ya da değiştirilebilir olarak değerlendirilmesi bu panelin içeriğidir

Panel 5 uyum gerektiren vazifeleri kapsar.. Bu panel yedi uyum vazifesinden oluşmaktadır. Bunlar semptomları yönetme, tedaviyi yönetme, sağlık çalışanları ile ilişki kurabilme, olumlu bir kendilik imajını sürdürebilme, aile ve arkadaşlarla ilişki kurabilme, duyguları yönetme, ve belirsiz geleceğe hazırlık yapabilmedir. Bu panelin ölçümlerinin yapılabilmesi adına bu tezde bir ölçek geliştirilmiştir. Bu ölçekle ilgili detaylı bilgi aşağıdadır.

Panel 6 problemle başa çıkma yöntemlerini kapsamaktadır. Panel 6 bu çalışmada Başa Çıkma Yolları ölçeği ile değerlendirilmiştir. Son panel ise sağlıkla ilgili sonuçlar, depresyon, stres, iyi olma durumu ve tedaviye uyum gösterme gibi faktörleri kapsamaktadır. Bu paneli değerlendirmek üzere, Bakım Veren İyi Olma Durumu Ölçeği, Beck Depresyon Ölçeği ve Potizif ve Negatif Duygulanım Ölçeği kullanılmıştır.

Bu model çerçevesinde “Otizm Bakım Verenleri için Uyum Ölçeği” geliştirilmiştir. Bu ölçek için 53 soruluk bir indeks geliştirilmiş ve 4 uzmandan geri bildirimler alınmıştır. Yapılan faktör analizleri sonucunda 2 faktörden oluşan 43 soruluk bir ölçek oluşturulmuştur. Faktörler “ Günlük Değişimlere Uyum” ve “Sağlıkla İlgili Değişimlere Uyum” olarak adlandırılmıştır (Otizm Bakım Verenleri için Uyum Ölçeği ile ilgili detaylı bilgi için Tablo 1’i inceleyebilirsiniz.)

Tablo 1. *Otizm Bakım Verenleri için Uyum Ölçeği için faktör yükleri, açıklanan varyanslar ve alfa katsayıları*

Madde	Faktörler		Madde Toplam *r*	Madde çıktığında *α* değeri
	Sağlıkla İlgili Değişimlere Uyum	Günlük Değişimlere Uyum		
S11 (Çocuğum kendine şiddet gösterdiğinde bunun sebebini anlayabiliyorum)	**.717**	-.104	.668	.884
S10 (Çocuğum kendine şiddet gösterdiğinde bununla başa çıkabiliyorum)	**.713**	.036	.644	.885
S14 (Çocuğum bir başkasına şiddet gösterdiğinde bunun sebebini anlayabiliyorum)	**.712**	.009	.623	.886
S3 (Çocuğumun isteklerini karşılayabiliyorum)	**.708**	.073	.658	.886
S6 (Çocuğum ağladığında bunun sebebini anlayabiliyorum)	**.675**	.086	.646	.886
S5 (Çocuğumun davranış problemi göstereceği zamanları önceden anlayabiliyorum)	**.671**	.026	.627	.886
S9 (Çocuğum bağırdığında bununla başa çıkabiliyorum)	**.665**	.122	.604	.887
S8 (Çocuğum bağırdığında bunun sebebini anlayabiliyorum)	**.661**	.058	.602	.887
S21 (Çocuğumun hangi alanlarda eğitime ihtiyaç duyduğunu anlayabiliyorum)	**.660**	.177	.585	.887
S12 (Çocuğum bana şiddet gösterdiğinde bununla başa çıkabiliyorum)	**.659**	.043	.574	.887
S2 (Çocuğumun ihtiyaçlarını anlayabiliyorum)	**.602**	-.018	.528	.889
S20 (Çocuğumun daha iyi bir eğitim alması ile ilgili neler yapacağımı biliyorum)	**.577**	.147	.535	.889
	.573	.200	.496	.890

Tablo 1. (Devam Ediyor)

Madde	Faktörler		Madde Toplam *r*	Madde çıktığında *α* değeri
	Sağlıkla İlgili Değişimlere Uyum	Günlük Değişimlere Uyum		
S19 (Çocuğumun ihtiyacı olan eğitim için gerekli kaynaklara ulaşabiliyorum)	**.502**	.417	.504	.890
S16 (Çocuğumun (eğer alıyorsa) özel eğitim sürecine uyum sağlayamadım)	**.444**	.130	.493	.890
S24 (Çocuğumun öğretmeni ile istediğim gibi iletişim kurabiliyorum)	**.392**	.161	.391	.893
S25 (Çocuğumun öğretmenine isteklerimi ifade edemiyorum)	**.340**	.-091	.316	.897
S4 (Çocuğumun ihtiyaçlarını karşılayamıyorum)	**.339**	.131	.324	.895
S22 (Doktor kontrollerine ve rapor alma-yenileme süreçlerine uyum sağlayamadım)	**.321**	.080	.320	.890
S42 (Kök ailem (kendi anne-babam ve kardeşlerim) ile yaşadığım problemleri sağlıklı bir şekilde çözebiliyorum)	.166	**.798**	.743	.894
S39 (Kök ailem (kendi anne-babam ve kardeşlerim) ile ilişkilerimi sağlıklı bir şekilde sürdürebiliyorum)	.154	**.770**	.703	.895
S41 (Çekirdek ailem (eşim ve diğer çocuklarım) ile yaşadığım problemleri sağlıklı bir şekilde çözebiliyorum)	.189	**.664**	.603	.897
S40 (Çekirdek ailem (eşim ve diğer çocuklarım) ile ilişkilerimi sağlıklı bir şekilde sürdürebiliyorum)	.093	**.655**	.551	.898
S47 (Arkadaşlarımla ilişkilerim sağlıklı bir şekilde sürdürebiliyorum)	.180	**.652**	.604	.897
S44 (Çekirdek ailemden (eşim ve diğer çocuklarım) beklediğim desteği onlara ifade edebiliyorum)	.167	**.648**	.590	.898
S38 (Dış görünüşüme özen gösterebiliyorum)	.350	**.633**	.697	.895

Tablo 1. (Devam Ediyor)

Madde	Faktörler		Madde Toplam *r*	Madde çıktığında *α* değeri
	Sağlıkla İlgili Değişimlere Uyum	Günlük Değişimlere Uyum		
S48 (Arkadaşlarımdan beklediğim desteği onlara ifade edebiliyorum)	.208	**.618**	.589	.898
S53 (Çocuğumun gelecekte ihtiyaç duyabileceği bakım için gerekli hazırlıkları yapabiliyorum)	.305	**.612**	.639	.897
S49 (Arkadaşlarımdan beklediğim desteği alabiliyorum)	-.008	**609**	.516	.899
S43 (Kök ailemden (kendi anne-babam ve kardeşlerim) beklediğim desteği onlara ifade edebiliyorum)	.110	**.605**	.549	.898
S52 (Çocuğumun gelecekte karşılaşabileceği ekonomik zorluklar için gerekli hazırlığı yapabiliyorum)	.361	**.585**	.613	.897
S46 (Kök ailemden (kendi anne-babam ve kardeşlerim) beklediğim desteği alamıyorum)	-.207	**.535**	.397	.901
S35 (Kendi öz bakımımı istediğim şekilde sağlayabiliyorum)	.206	**.519**	.549	.898
S32 (Otizm spektrum bozukluğu tanısı almış bir çocuğun ebeveyni olarak duygusal ihtiyaçlarımı karşılayamıyorum)	.141	**.518**	.513	.899
S51 (Çocuğumun gelecekte alması gereken eğitim için gerekli hazırlığı yapabiliyorum)	.460	**.516**	.564	.898
S50 (Çocuğumun gelecekte karşılaşabileceği sağlık problemleri için gerekli hazırlığı yapabiliyorum)	.487	**.510**	.588	.897
S45 (Çekirdek ailemden (eşim ve diğer çocuklarım) beklediğim desteği alamıyorum)	-.016	**.491**	.401	.901
S37 (Kendimden hoşnutum)	.579	**.491**	.604	.897
S34 (Kendime istediğim kadar vakit ayıramıyorum)	-.154	**.467**	.376	.902
S36 (Fiziksel sağlığıma dikkat edemiyorum)	-.132	**.435**	.353	.902
S30 (Otizm spektrum bozukluğu tanısı almış bir çocuğun ebeveyni olarak olumsuz duyguların yarattığı etkileri kontrol edebiliyorum)	.535	**.407**	.517	.899
S33 (Kendi fiziksel bakımımı istediğim şekilde sağlayabiliyorum)	-.020	**.332**	.279	.920
S31 (Otizm spektrum bozukluğu tanısı almış bir çocuğun ebeveyni olarak olumsuz duygularımla başa çıkamıyorum)	.330	**.325**	.390	.901

Tablo 1. (Devam Ediyor)

Madde	Faktörler		Madde Toplam *r*	Madde çıktığında *α* değeri
	Sağlıkla İlgili Değişimlere Uyum	Günlük Değişimlere Uyum		
Özdeğer	11.75	.4.95		
Açıklanan varyans (%)	27.33	11.52		
Alfa katsayısı	.894	.903		

Not. Maddeler yüklendikleri faktörün altında bold karakterlerle belirtilmiştir.

Bakım verenlerin depresif semptom, olumlu duygulanım, olumsuz duygulanım, temel ihtiyaçların karşılanma ve yaşamsal faaliyetleri yerine getirme seviyelerinin yordayan etmenleri belirlemek üzere beş ayrı hiyerarşik regresyon analizi yapılmıştır.

Bu çalışmanın sonuçları otizm spektrum bozukluğu tanısı sonrası gerçekleşen değişimlere uyum becerisinin bakım veren depresif semptomları, pozitif ve negatif duygulanımı ve iyi olma hali göstergeleri üzerinde oldukça güçlü bir etkisi olduğunu ortaya koymuştur.

İlk basamak değişkenlerinden Psikolojik Bozukluk ve Çocuğun Yaşı, ikinci basamak değişkenlerinden Algılanan Sosyal Destek, üçüncü basamak değişkenlerinden Uyum ve dördüncü basamak değişenlerinden Problem Odaklı Başa Çıkma anlamlı bir şekilde Depresif Semptomları yordamaktadır.

Benzer bir şekilde ilk basamak değişkenlerinden Psikolojik Bozukluk, , ve üçüncü Basamak Değişkenlerinden Uyum anlamlı bir şekilde Olumsuz Duygulanımı yordamaktadır.

Yine ilk basamak değişkenlerinden Psikolojik Bozukluk, ikinci basamak değişkenlerinden Algılanan Sosyal Destek ve Öz Yeterlilik, üçüncü basamak değişkenlerinden Uyum ve dördüncü basamak değişenlerinden

Problem Odaklı Başa Çıkma anlamlı bir şekilde Olumlu Duygulanımı yordamaktadır.

Diğer bir taraftan ilk basamak değişkenlerinden Bakım Verme için Destek Veren Birilerinin Olması, ikinci basamak değişkenlerinden Algılanan Sosyal Destek ve üçüncü basamak değişkenlerinden Uyum anlamlı bir şekilde kişinin Basit İhtiyaçlarını gidermesini yordamaktadır.

Son olarak, ilk basamak değişkenlerinden Psikolojik Bozukluk, ikinci basamak değişkenlerinden Bakım Verenin Yaşı ve Çocuğun Davranışları ve üçüncü basamak değişkenlerinden Uyum anlamlı bir şekilde kişinin Yaşam Aktivitelerini gidermesini yordamaktadır.

Bu hiyerarşik regresyon analizlerin sonucunda ortaya çıkan özet tablo için Tablo 2'yi inceleyebilirsiniz.

Tablo 2. *Hiyerarşik Regresyon Özet Tablosu*

	Depresif Semptomlar	Olumsuz Duygulanım	Olumlu Duygulanım	Basit İhtiyaçlar	Yaşam Aktiviteleri
İlk Basamak Değişkenleri					
Bakım Verme İçin Destek Veren Birileri				Anlamlı(+)	
Psikolojik Bozukluk	Anlamlı (+)	Anlamlı (+)	Anlamlı (-)		Anlamlı (-)
Çocuğun Yaşı	Anlamlı (-)				
İkinci Basamak Değişkenleri					
Cinsiyet					
Sosyoekonomik Seviye					
Algılanan Sosyal Destek	Anlamlı (-)		Anlamlı (+)	Anlamlı (+)	
Yaş					Anlamlı (+)
Çocuğun Davranışları					Anlamlı (+)
Eğitim					
Öz-Yeterlilik			Anlamlı (+)		
Üçüncü Basamak Değişkenleri					
Uyum	Anlamlı (-)	Anlamlı (-)	Anlamlı (+)	Anlamlı (+)	Anlamlı (+)
Dördüncü Basamak Değişkenleri					
Duygu Odaklı Başa Çıkma					
Problem Odaklı Başa Çıkma	Anlamlı (-)		Anlamlı (+)		

Not. (-) olumsuz yönde ilişkili ve (+) olumlu yönde ilişkili

4. Üçüncü Çalışma: Otizm Spektrum Bozukluğu Bakım Verenlerine Yönelik Grup Müdahale Programı

Üçüncü çalışma, birinci çalışmada elde edilen bulgular ışığında bir grup müdahale programı geliştirme ve uygulamayı kapsamaktadır. Bu çalışma birinci çalışmanın katılımcılarından farklı 6 katılımcı ile gerçekleştirilmiştir.

Bu müdahale programı 7 hafta ve her oturum yaklaşık 2 saat olacak şekilde gerçekleştirilmiştir. Grup müdahale programı bu tezin birinci çalışmasında ortaya çıkan temalar doğrultusunda, Judith Beck'in *Cognitive Behavioral Therapy* (2011), Folkman ve Lazarus'un *Stress, Appraisal and Coping* (1984), David Burns'un *Feeling Good: The New Mood Therapy* (1980), Mental Bozuklukların Tanısal ve Sayımsal El Kitabı 5 (2013) ve bu tezde kullanılan bazı makaleler referans alınarak geliştirilmiştir. Üçüncü çalışmanın hipotezleri şu şekildedir:
Yedi haftalık grup müdahale programının sonunda katılımcıların:

1- Müdahale öncesi puanlar müdahale sonrası puanlarla kıyaslandığında depresif semptomlarında anlamlı bir azalma,
2- Müdahale öncesi puanlar müdahale sonrası puanlarla kıyaslandığında olumsuz duygulanım puanlarında anlamlı bir azalma,
3- Müdahale öncesi puanlar müdahale sonrası puanlarla kıyaslandığında olumlu duygulanım puanlarında anlamlı bir artma,
4- Müdahale öncesi puanlar müdahale sonrası puanlarla kıyaslandığında basit ihtiyaçlar puanlarında anlamlı bir artma,
5- Müdahale öncesi puanlar müdahale sonrası puanlarla kıyaslandığında günlük aktiviteler puanlarında anlamlı bir artma beklenmektedir.

Birinci haftada bakım veren annelere otizm spektrum bozukluğu ile ilgili psikoeğitim verilmiştir. Bu oturumda otizm spektrum bozukluğunun çeşitleri, tanı kriterleri, tanı konma yaşı gibi konulara değinilmiş, bozukluğun tarihsel süreci işlenmiştir. Buna ek olarak ailelerin otizm spektrum bozukluğu ile ilgili bilgileri tartışılmış ve değerlendirilmiştir. İkinci ve üçüncü haftalarda ailelerin otizm spektrum bozukluğu ile ilgili duyguları, bu duyguları ile ilişkili düşünceleri üzerine çalışılmıştır. Bilişsel çarpıtmalar ve düşünce hataları öğretilmiş ve aileler ile rasyonel düşünme üzerine çalışmalar gerçekleştirilmiştir. İkinci oturumda ailelere düşünce takip formu gösterilmiş ve ailelerden bu formu hafta içlerinde doldurmaları istenmiştir. Üçüncü oturuma dolu olarak gelen formlar teker teker incelenmiş, grup üyelerinin birbirlerinin düşünceleri ile ilgili bilişsel çarpıtmalar üzerinden geri bildirim vermeleri istenmiştir. Bu geribildirimleri takiben grup müdahale programı yürütücüsü de aileler geri bildirimler vermiş ve rasyonel düşünme ile ilgili katılımcıları teşvik etmiştir. Dördüncü haftanın ana konusu strestir. Bu oturumda ailelere stres semptomları ile ilgili bilgi verilmiş ve stresle başa çıkarken işlevsel olan ve işlevsel olmayan başa çıkma stratejileri üzerine çalışılmıştır. Beşinci hafta sosyal desteği artırma, sosyal desteği kabul etme gibi konuları kapsamaktadır. Altıncı haftada gelecekte aileleri nelerin beklediği ile ilgili çalışılmış, çocukların yasak hakları ve gelecekte karşılaşabilecekleri zorluklarla nasıl başa çıkacakları üzerinde durulmuştur. Son hafta ise değerlendirme modülü olarak planlanmıştır. İlk 6 oturumun sonunda aşamalı kas rahatlama egzersizleri gerçekleştirilmiş ve bakım veren annelerin bu egzersizleri kendi başlarına da yapması teşvik edilmiştir. Grup müdahale programının son haftası değerlendirilmeye ayrılmıştır. Bu oturumda ailelerden geri bildirim alınmıştır. Altı haftalık grup müdahale programı süresince ailelere nelerin iyi geldiği, neleri değiştirmek isteyebilecekleri konuşulmuştur.

Uygulanan müdahale programının sonunda otizm tanılı çocukların birincil bakım verenlerinde pozitif duygulanım ve iyilik hali göstergeleri (temel ihtiyaçların karşılanması ve yaşamsal faaliyetlerin yerine getirilmesi) puanlarının çalışma öncesi puanlarına göre anlamlı bir şekilde arttığı görülmüştür. Diğer bir taraftan depresif semptom skorları ve negatif duygulanım puanlarının anlamlı bir şekilde düşüş göstermediği ortaya konmuştur. Bu durum ailelerin negatif duygu ve semptomlarını müdahale programından sonra daha açıklıkla ortaya koyabilmelerine bağlanmıştır. Bu açıklama grup müdahale programının başında ve sonunda elde edilen ölçek puanlarının değişimleri üzerinden örneklendirilmiştir. Şöyle ki grup müdahale programının başında depresif semptom puanı altmış üç üzerinden üç olan bir katılımcının, grup müdahale programı sonucunda bu puan yedi ‘ye çıkmıştır. Benzer bir şekilde negatif duygulanım puanının en düşük on olduğu Pozitif ve Negatif Duygulanım ölçeğinde bir katılımcının negatif duygulanım skoru müdahale öncesinde on bir, müdahale sonrasında ise on yedi olmuştur. Müdahale öncesi puanların bu kadar düşük olması, katılımcıların olumsuz duygularını ifade etmekte zorlandıkları şeklinde değerlendirilmiş ve bu değerlendirme Türk toplumunun kolektivisttik bir toplum olması üzerinden açıklanmıştır. Müdahale programı süresince katılımcılar olumlu ve olumsuz duygularını ifade etme yönünden teşvik edilmiştir ve depresif semptomlar ve negatif duygulanım puanlarında gözlemlenen bu iki değişiklik bu teşvikin işe yaramasıyla açıklanmıştır. Depresif semptomlar ve negatif duygulanım puanlarında yukarıda yazan dışında başka bir yükselme olmamıştır. Bu durum yapılan açıklamayı destekler niteliktedir. Diğer bir taraftan katılımcı sayısının sınırlı olması, kontrol grubunun olması ve takip ölçümlerinin gerçekleştirilememiş olması bu çalışmanın sınırlılıkları olarak göze çarpmaktadır.

APPENDIX L: TEZ FOTOKOPİSİ İZİN FORMU

ENSTİTÜ

Fen Bilimleri Enstitüsü ☐

Sosyal Bilimler Enstitüsü ☒

Uygulamalı Matematik Enstitüsü ☐

Enformatik Enstitüsü ☐

Deniz Bilimleri Enstitüsü ☐

YAZARIN

Soyadı : Yalçın
Adı : Çağdaş
Bölümü : Psikoloji

TEZİN ADI (İngilizce) : CAREGIVER PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: NEED ASSESSMENT, MODEL TESTING, AND INTERVENTION STUDIES

TEZİN TÜRÜ : Yüksek Lisans ☒ Doktora ☐

1. Tezimin tamamından kaynak gösterilmek şartıyla fotokopi alınabilir. ☐
2. Tezimin içindekiler sayfası, özet, indeks sayfalarından ve/veya bir bölümünden kaynak gösterilmek şartıyla fotokopi alınabilir. ☒
3. Tezimden bir bir (1) yıl süreyle fotokopi alınamaz. ☐

TEZİN KÜTÜPHANEYE TESLİM TARİHİ: