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Examining the Factors Influencing the Stress Levels in Families of Children with Autism

Otizmli Çocukları Olan Ailelerin Stres Düzeylerini Etkileyen Faktörlerin İncelenmesi

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Abstract

This study examines the influence of coping strategies, social support systems and family resilience levels on the perceived stress levels of Turkish families of children with autism. The sample of this cross-sectional study consists of 213 mothers and 87 fathers of children diagnosed with autism. Perceived Stress Scale, Coping Styles Scale Short Form, Revised Parent Social Support Scale and Family Resilience Scale Turkish Forms were used. In the analysis of the data, the normal distribution was examined and used in

Öz

Bu çalışma, baş etme stratejilerinin, sosyal destek sistemlerinin ve aile dayanıklılık düzeylerinin Türk otizmli çocuk ailelerinin algılanan stres düzeyleri üzerindeki etkisini incelemeyi amaçlamaktadır. Bu kesitsel araştırmanın örneklemini otizm tanısı almış çocuğu olan 213 anne ve 87 baba oluşturmaktadır. Araştırmada Algılanan Stres Ölçeği, Başa Çıkma Tarzları Ölçeği Kısa Formu, Gözden Geçirilmiş Ebeveyn Sosyal Destek Ölçeği ve Aile Yılmazlık Ölçeği Türkçe Formları kullanılmıştır. Verilerin analizinde normal

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multiple regression analysis techniques for predicting the dependent variable based on the independent variables to understand the relationship between dependent and independent variables. Regression analysis revealed that the number of children and diagnosis age of the child with autism positively affect the family stress level. All of these variables explained 14% of the total variance. One of the most important findings of this study is that the stress levels of mothers were found to be higher than fathers. Parents' age, education, income level, number in the birth order of child with autism, time of autism noticed, active and passive coping methods and family resiliency negatively affected family stress level. In addition, further study is needed to investigate psychosocial interventions that decrease stress levels and facilitate active coping strategies among families who have children with autism.

Keywords: Autism, Families of children with autism, Stress levels, Coping styles, Social support

dağılım incelenmiş ve bağımlı ve bağımsız değişkenler arasındaki ilişkiyi anlamak için bağımsız değişkenlere dayalı olarak bağımlı değişkeni tahmin etmek için çoklu regresyon analizi tekniklerinde kullanılmıştır. Regresyon analizi, çocuk sayısı ve otizmli çocuğun tanı yaşının aile stres düzeyini pozitif yönde etkilediğini ortaya koymuştur. Tüm bu değişkenler toplam varyansın %14'ünü açıklamaktadır. Bu çalışmanın en önemli bulgularından biri, annelerin stres düzeylerinin babalardan daha yüksek bulunmasıdır. Ebeveynlerin yaşı, eğitimi, gelir düzeyi, otizmli çocuğun doğum sırasındaki sayısı, otizmin fark edilme zamanı, aktif ve pasif baş etme yöntemleri ve aile dayanıklılığı aile stres düzeyini olumsuz yönde etkilemektedir. Ayrıca, otizmli çocuğa sahip ailelerin stres düzeylerini azaltan ve aktif başa çıkma stratejilerini kolaylaştıran psikososyal çalışmalara gereksinim vardır.

Anahtar Kelimeler: Otizm, Otizmli çocuğu olan aileler, Stress düzeyleri, Baş etme biçimleri, Sosyal destek

Introduction

Autism spectrum disorder (ASD) is a complex developmental condition that involves persistent challenges in social interaction, speech and nonverbal communication, and restricted/repetitive behaviours (APA, 2013). According to the World Health Organization (WHO), the prevalence of autism worldwide is 1/160. The frequency of autism was reported as 1/150 in

2000, 1/110 in 2006, 1/69 in 2012, and 1/59 in 2014 (CDC, 2018). When the frequency of autism is examined by years, it is revealed that autism increases day by day.

In the process, before their children receive a particular diagnosis, families feel intensely confused in their emotions. With the diagnosis of autism, families often experience feelings of sadness, confusion, loss, denial, guilt or depression (Altiere & Kluge, 2009; Kuhn & Carter, 2006).

While cognitive, social, emotional, motor development, language, and communication characteristics of children with autism are different from those of other children, the fact that their appearance characteristics are similar to other children causes families to be caught unprepared for the process and not to know what to do and how to behave. This situation has an impact on the stress experienced by families, and their self-confidence. As Wing (2012) stated, the joint request of parents is to feel that there is a simple key that will solve all the problems experienced. However, no two children with autism are alike. In this context, parents also encounter many behavioural patterns that are difficult to define (Kavak, 2007). Caring for children, not being able to spare time for other children, being blamed by spouses or family members are among the most challenging difficulties. Families may experience stress or feel psychologically tired due to these difficulties.

Research shows that being a parent of a child with autism can be more challenging, and stressful than parenting a child with a chronic illness or developmental disability (Tunali & Power, 2002; Sounders, DePaul, Freeman & Levy, 2002). Marcus, Kunce and Schopler (2005) listed the stress factors experienced by families as follows: a) Not having enough information after the diagnosis and not knowing what to do, b) here are differences in the development of their children, c) their children's appearances are regular, d) children's communication and behaviour problems, e) family members do not get the same answers to their approach to children, f) behaviours that may leave the family in a difficult situation in the society, g) the need to communicate with many different experts, h) here are many therapies available, and it is the responsibility to decide which therapy will be most appropriate and beneficial for their child.

An extensive number of published studies have examined the stress levels in families of children with autism. Studies rarely synthesise many factors, such as the distribution of responsibilities, boundaries between family members, and the personal meanings of having a family member with autism (Lecavalier, Leone, & Wiltz, 2006).

Studies conducted on this subject show that the stress levels of parents with a child with a disability are significantly higher than the stress levels of parents with a child with a typically developing child (Boyd, 2002; Dunn et al., 2001; Gray, 2006; Luther, Canham, and Cureton, 2005). There are also related studies showing that families with children with autism have higher levels of stress compared to families with children with other disabilities (Estes, Munson, Dawson,

Koehler, Zhou & Abbott, 2009; Koegel et al., 1992; Lee, 2009; Sabih & Sajid, 2008; Smith, Oliver and Innocenti, 2001). These studies reveal the stress experienced by families struggling with the difficulties of having a child with autism, the effects of these stresses on family members, the existing coping methods used by families, and the importance of meeting the needs of families. Herken et al. (2000) stated that since the first-degree caregiver is primarily the mother, mothers are more affected by this situation, especially their stress, and anxiety levels.

Hastings (2005) investigated the effects of the behaviour problems of the autistic child, and the psychological health of the spouse on the stress levels of parents with a child with autism. Eighteen couples with a child with autism participated in the study. As a result of the research, no difference was found between the stress, and depression levels of the mothers, and fathers. In contrast, the mothers' anxiety levels were found to be higher. As a result, it was seen that the problems related to the child and the spouse were not practical on the fathers' stress levels. However, the behavioural problems of the child and the psychological health status of the father were influential on the stress level of the mother.

In a study conducted by Lindholm (2007) with families with children with autism, it was observed that the perception of family quality of life decreased as the stress level increased. Another noteworthy point is that the family's acceptable use of support systems is a factor that facilitates coping with problems and reduces the family's stress level (Aslan, 2010).

A study comparing the stress of parents with children diagnosed with autism and intellectual disability determined that parents of children with autism experience more stress than parents of children with intellectual disabilities. While it was determined that problem-focused coping was used the most to cope with stress and it was tried to obtain as much information as possible to solve the problem; it was determined that the least used strategy was to grind their teeth and continue as if nothing had happened (Yurdakul, Girli, Özekes, & Sarısoy, 2002).

The field of family-focused autism research is still underdeveloped, as understanding the complex and reciprocal effects between autism and other family members is emerging (Orsmond & Seltzer, 2007).

Stress in parents of children on the autism is dependent on a number of factors which seem to be interrelated and complex. Difficulties experienced by families such as the restriction of their social environment due to the care of their children with autism, the decrease in leisure and social activities, the change/end of their professional life and their exclusion from society are highly influential on their social lives. For these reasons, the stress experienced by families who move away from social life increases. Previously used coping mechanisms may be insufficient.

Coping is the process by which an individual makes an effort to manage the situation which he has evaluated as challenging or demanding.

Social support is a critical factor in reducing the negative psychological impact of raising a child on the autism, or other developmental disabilities (Ekas, Lickenbrock, & Whitman, 2010). Social support has been shown to be associated with decreased psychological distress as well as increased parenting efficacy in parents of children on the autism spectrum disorder (Weiss, 2002; Bromley, etc., 2004; Lindsey, & Barry, 2018). Regarding family support, Morya et al. (2016), stated that there is a strong relationship between perceived stress and family support.

In other study examining stress and resilience in parents of children with intellectual and developmental disabilities, optimism and social support are important in coping (Peer & Hillman, 2014). Having coping skills also brings resilience (Kenny, 2000). Coping strategies are the behavioral and cognitive responses of the individual to stressful situations and ensure resilience (Dolbier & Steinhardt, 2008). Maddi and Khoshaba (1984) state that indomitable individuals respond more effectively to stressful situations by using more preventive coping strategies.

However, no research has been found focusing on the relationship between perceived stress and the psychosocial characteristics of Turkish families of children with autism. This study aims to examine the influence of coping strategies, social support systems and family resilience levels on the perceived stress levels of Turkish families of children with autism.

The research questions of the study are listed below:

1. Are there significant relationships between perceived stress levels and families with autism coping strategies, social support systems and family resilience levels?

2. Are there significant relationships between perceived stress levels and sociodemographic characteristics (age, education, monthly income, etc.)?

3. To what extent do families who have children, coping strategies, social support systems and family resilience, sociodemographic characteristics, and the other factors explain perceived stress levels?

Methods

Participants and Criteria for the Study

The study was conducted with Turkish parents with children diagnosed with autism who voluntarily agreed to participate in the study using the convenience sampling method. The sample of the study Ankara and Kırıkkale are determined in extensive Private Education and Rehabilitation Centres. A list of Special Education and Rehabilitation Centers serving in Ankara and Kırıkkale was created, and it was tried to get permission from the centres either face to face

or via phone. Considering their socio-economic characteristics, families who volunteered to participate in the study receiving service from Special Education and Rehabilitation Centers in Çankaya, Çubuk, Pursaklar and Karapürçek were included in the sample. Two hundred thirteen mothers and 87 fathers were reached in the research.

Each participant was informed, before the interview, about the purpose of the study, written informed consent was obtained, and participants were told that they had the right to refuse participation and could withdraw at any time. Ten parents did not want to participate in the study during this period due to sadness and disappointment. Written informed consent was obtained, and participants were told that they had the right to refuse participation and could withdraw at any time.

Parents answered a compound questionnaire composed of different instruments to evaluate sociodemographic, stress-coping-perceived social support and resiliency levels. One researcher administered the questionnaire from July to November 2019.

During the data collection process, all in Private Education and Rehabilitation Centres were interviewed to collect data for our research. Some parents refused to participate in the study due to sadness and disappointment. The researchers did not record the number of parents who refused to collect data. Three hundred (300) people have children with autism completed the questionnaire. For this reason, missing data is absent in surveys. Finally, three hundred (300) parents (213 female, 87 male) participated in the study. The Hacettepe University ethical review board approved written informed consent and obtained it from each participant before the interview. The researchers reached 24 centres that allowed the study.

Sociodemographic characteristics of the participants are examined; the majority of the study participants are mothers (71%). Average age is 39.14 (SD = 8.23). Almost all mothers and fathers are married (97%), and those with two children make up almost half (46%). The proportion of those with a medium level of education (secondary school, high school) is almost half (43.3%). When the education level of mothers and fathers who have children with autism are examined separately, it is found out that almost one-third of the mothers (34.7%) has a secondary level of education. Almost one-fifth of the fathers (18.7%) has a high level of education. When the occupational distribution of mothers and fathers is examined, half of the mothers (54.3%) are housewives. When the occupation distribution of fathers is examined, it is seen that three-tenth of the fathers (10.3%) work in the service sector. When the monthly income distribution of the family is examined, it is seen that a significant proportion (29.3%) of the mothers has a monthly income between 2000 TL and 3000 TL; one-tenth of the fathers (14.3%) has a monthly income of 5001 TL or above.

Instruments

In the study, Perceived Stress Scale, Coping Styles Scale Short Form (CBES-SF), Revised Parents Social Support Scale (YASDÖ), Family Resilience Scale (ASI) were used. In addition to these scales, the Personal Information Form prepared by the researcher was used to determine the sociodemographic information of the families and the children. All the instruments were combined to create a single questionnaire. The data collection process was carried out by the researcher directly through face-to-face interviews. The data collection tools used in the study are addressed in detail below. The level of perceived stress was the dependent variable.

Sociodemographic Data Form

There are 25 questions in the prepared form, most of which are closed-ended. The questions consist of;

• Questions for families such as a role in the family, age, educational status, marital status, family structure, total income, number of children, gender of the child with autism, child's order of birth.

• Questions about children such as who first noticed the child with autism, when they noticed it, how old he/she was when he/she was diagnosed, whether he/she had any other illnesses, and his/her educational status,

• To learn the effects of autistic children on family members; questions about how they are affected by the presence of a child with autism, how it affects their relationship with the spouse, the situation of taking care by the spouse, if any, the relationships of other siblings, the thoughts of spending time for themselves, the status of receiving psychological support,

• Questions about the most supportive person about their children's autism, the support they need the most, and their future expectations for their children.

Perceived Stress Scale (PSS)

Perceived Stress Scale was developed by Cohen, Kamarck, and Mermelstein (1983). Turkish adaptation was made by Eskin et al. (2013), and it has 14 items and measures the stress level. A score between 0 and 4 is given to the PSS that measures the perceived stress level. Scores vary between 0-56. The Turkish PSS can be used to measure the perceived stress of people.

The internal consistency coefficients of Turkish PSS-14, PSS-10 and PSS-4 were calculated as 0.84, 0.82 and 0.66, respectively; test-retest reliability coefficients were calculated as 0.87, 0.88 and 0.72, respectively. It has been found that the stress scores obtained from the long and short forms of PSS have a positive correlation with life events and depression and a negative correlation coefficient with life satisfaction, self-esteem, and perceived social support scores.

Factor analysis has revealed that the PSS-14 and PSS-10 have had a two-factor structure: poor self-efficacy and perception of stress/discomfort.

In this study, the Cronbach's alpha internal consistency coefficient was found as .89 for the PSS-10 subscale (perception of poor self-efficacy), .59 for the PSS-4 subscale (stress/discomfort), and .90 for the total stress scale.

Coping Strategies Scale Short Form

Coping Scale Short Form; was developed by Carver (1997) using fewer items based on the long-form Coping Scale. The Turkish adaptation study of the scale was carried out by Bacanlı, İlhan, and Sürücü (2007) on a sample of 275 persons. The scale consisting of 28 items does not contain any reversely loaded items. Coping strategies scale consists of the subscales of; "Using instrumental social support, humorous approach, focusing on and revealing emotions, substance use, acceptance, giving up other activities, religious coping, denial, behavioural disinterest, mental disinterest, self-restraint, positive reinterpretation, using emotional, social support and planning". The sum of the items 15 and 26 constitute using instrumental social support subscale, the sum of the items 7 and 20 constitute the humorous approach subscale, the sum of the items 1 and 13 constitute focusing on and revealing emotions subscale, the sum of the items 12 and 19 constitute the substance use sub-scale. The sum of items 5 and 25 is the acceptance subscale, the sum of the items 11 and 17 are leaving the other activities subscale, the sum of the items 6 and 27 is the religious coping subscale, the sum of the items 3 and 23 is the denial sub-scale, the sum of the items 4 and 10 are the behavioural disinterest subscale, the sum of items 2 and 24 is the mental disinterest subscale, the sum of items 28 and 8 is the self-limiting subscale. The sum of items 14 and 21 is a positive reinterpretation. The total of items 9 and 18 is the emotional, social support subscale, the items 16 and 22 are the planning subscale. Scale items are marked as (1) I never do such a thing, (2) I rarely do such a thing, (3) I do this moderately, (4) I mostly do this.

As a result of the exploratory factor analysis, a structure with 14 factors consisting of two items was obtained. The variance explained by all factors is 80.37%. In order to test the adaptive validity of the scale, its relationships with social desirability, life satisfaction, self-esteem and type A personality were examined. Cronbach alpha coefficients of the factors range from 0.39 to 0.92. It was observed that the correlation coefficients of the factors took values between .44 and .90 in the measurements made in two-week intervals for the test repetition reliability of the CBD-SF.

In this study, the Cronbach's alpha internal consistency coefficient was .60 for problem focused coping, .51 for emotion focused coping.

Revised Parental Social Support Scale (RPSSS)

The Revised Parental Social Support Scale (RPSSS) was developed by Kaner (2010). The subjects consisted of 245 parents (125 parents of children with disabilities and 120 parents of children with non-disabled). It is a scale that evaluates the social support perceptions of parents who have a child or children with disabilities. RPSSS consists of 4 subscales as Social Cooperation Support, Information Support, Emotional Support, Care Support. The items of RPSSS are scored in two different ways, namely their degree of having the support and how satisfied they are with the existing supports. Scales results' showed that RPSSS could be used to understand parents perceived social support and satisfaction with these supports.

RPSSS has 31 items in total, including the options of "none", "rarely exists", "sometimes exists", "always exists", which are used to determine whether the parents have any social support or not and the options of "not satisfied", "slightly satisfied", "satisfied" and "very satisfied" which are prepared to measure the satisfaction from the social support received by the parents (PSSSS).

Alpha coefficients were identified as 0.83-0.95 for RPSSS-ASDD and 0.85-0.96 for RPSSS-ASDMD. Spearman-Brown split-half reliability coefficients were determined as 0.86-0.92 for RPSSS-ASDMD and 0.84-0.96 for RPSSS-ASDMD.

In this study, the Cronbach's alpha internal consistency coefficient was found as .94 for the social togetherness support subscale, .95 for the information support subscale, .94 for the emotional support subscale, .98 for care support subscale, .98 for the total.

In this study, the Cronbach's alpha internal consistency coefficient was .97 for the social togetherness satisfaction support subscale, .97 for the information support satisfaction subscale, .97 for the emotional support satisfaction subscale, .94 for the care support satisfaction subscale, and .99 for the total satisfaction.

Family Resilience Scale (FRS)

The Family Resilience Scale, developed by Kaner and Bayraklı (2010), aims to measure the resilience levels of mothers and fathers. The scale subjects consisted of parents of 524 children *(105 parents of children with disabilities and 419 parents of children with no disability)*. The scale consists of 37 items. It includes the sub-dimensions of bellicosity, self-competence, commitment to life and self-control. (1) The scale is a five-point Likert-type measuring instrument ranging from *"(1) it describes me very well (5) to it does not describe me at all.*" A high score from the scale means that resilience is high in parents. Results revealed that FRS included 37 items under four factors and had adequate psychometric properties.

Within the scope of the validity studies of the scale, Principal Components Analysis (PCA) was performed first, and the accuracy of the resulting structures was tested with Confirmatory Factor Analysis (CFA). The fit index values obtained as a result of DFA was found as following:

RMSEA: 0.046; RMR: 0.044; NFI = 0.84; NNFI: 0.90; CFI: 0.91; GFI: 0.88; AGFI: 0.87. Within the scope of the reliability studies, Cronbach alpha values were found to be 0.54-0.91; test-retest reliability values were found to vary between 0.33-0.80.

In this study, the Cronbach's alpha internal consistency coefficient was found to be .95 for the combativeness sub-dimension, .94 for the self-efficacy sub-dimension, .94 for the commitment to life sub-dimension .71 for the self-control sub-dimension, and .98 for the scale total.

Statistical Analysis

The analyses were conducted using the SPSS program. Statistical analyses included descriptive statistics, reliability testing, and Pearson product moment correlation among variables. In descriptive statistics, proportion is used to describe categorical and numerical variables; mean and SD are used to describe continuous variables. Means, standard deviations and possible scale ranges were used to identify both the perceived stress scores, social support score, resilience score and the types of coping strategies used most frequently by parents of children with autism. Pearson correlation coefficients were calculated to assess the relationship between perceived stress, social support, resilience, coping strategies and demographic variables. All variables were examined for normality of distribution and outliers. The skewness kurtosis values of all variables vary between -2.0 and + 2.0.

In the analysis of the data, the typical distributions of the data were examined. Pearson correlation coefficient was used to determine correlations between variables, express the degree and direction of correlations, and analyse scale scores. The internal correlation was also analysed; significant variables at 0.01 were included in the regression analysis. Hierarchical multiple regression analysis was conducted to find the capacity of independent variables to interpret effects on dependent variables, that is, which variable has the most significant effect on a family's perceived stress. The primary data analysis method used in this study is hierarchical multiple regression analysis. Variables were entered into the regression equation in a predetermined order based on conceptual significance. The regression was set to a confidence interval of 0.05 (CI). In hierarchical regression, independent variables are analysed in blocks in a particular order according to logical and empirical bases. In this respect, hierarchical regression analysis makes it possible to provide a model for the factors that affect the perceived stress of families of children with autism. In this study, independent variables were analysed in different orders. The model that best explains the perceived stress of families with children with autism was presented.

Results

Table 1: Sociodemographic Features of Children with Autism

Sociodemographic Features of Children with Autism	N	%
Number in Birth Order		
1	135	45
2	118	39.3
3	35	11.7
4 and more	12	4
Gender		
Boys	220	73.3
Girls	80	26.7
Age		
0-2 age (Infancy)	11	3.7
3-6 age (The first childhood)	113	37.7
7-11 age (Elementary school term)	96	32
12-18 age (Adolescence)	67	22.3
18 age and over (Youth period)	13	4.3
Educational Status		
Special Education Application Center	103	34.3
Nursery/Kindergarten and Special Education and Rehabilitation Center		27.3
Special Education and Rehabilitation Center	53	17.7
Inclusive Education	31	10.3
Special Subclass	20	6.7
High School	11	3.7
The first person to notice the child		
Mother	228	76
Doctor	29	9.7
Family elders	25	8.3
Neighbor- friends	7	2.3
Teacher	6	2
Father	3	1
Sibling	2	.7
Notice Age of Child with Autism		
First 6 months and below	16	5.33
6 motnhs -1 age range	56	18.67

1-2 age range	127	42.33
2-3 age range	64	21.33
3 years and later	37	12.34
Diagnosis age		
1-3 age range	231	77
4-5 age range	60	20
6 age and over	9	3
The child has another disease	35	11.7
Average age, Median (SS); Interval	**8.86 (5.41); 1-42**	
Diagnosis age Average age, Median (SS); Interval	**3.1 (1.24); 1-14**	

When the findings are analysed according to birth order, almost half (45%) of children with autism rank as the first, the majority of the children are males (73.3%). A significant proportion (37.7%) of the children are in the first childhood period between the ages of 3-6. One-third of the children (34.3%) go to the Special Education and Application Centre.

It has been found out that the first person to notice that children have autism has been chiefly the mothers (76%), with the rates of fathers (1%) and siblings (0.7%) being in the last. We found that the children are generally noticed between the ages of 1-2 years (42.3%), and the diagnosis has been made mostly (77%) between the ages of 1-3. Most of the children do not have any other disorder accompanying autism (88.3%).

Table 2: Means and standard deviations of Family Resilience Scale, Coping Scale, Renewed Scale of Parents Social Support and Perceived Stress of the participants (n = 300).

Variables	M	SD	Range	Min.	Max.
Families' Perceived Scale Values					
PSS-10	23.64	6.3	40	0	40
PSS-4	9.20	2.53	16	0	16
Total	32.85	8.7	56	0	56
Coping Score	11,42	10,15		0	46
Active_coping	6.04	1.40	6	2	8
Religious coping	7.44	1.14	6	2	8
Use_of_instrumental_support	6.64	1.41	6	2	8
Planning	6.5	1.47	6	2	8
Acceptance	6.45	1.51	6	2	8
Positive_reframing	6.35	1.52	6	2	8
Use_of_emotional_support	5.14	1.54	6	2	8
Self_distraction	5.82	1.54	6	2	8

Venting	5.56	2.04	6	2	8
Behavioural disinterest	3.51	1.55	6	2	8
Mental disinterest	4.81	1.66	6	2	8
Humor	4.51	2.08	6	2	8
Denial	4.30	1.98	6	2	8
Substance use	2.55	1.24	6	2	8
Problem-focused coping	38.51	6.07	27	21	48
Emotion-focused coping	35.91	5.90	30	24	54
Renevew Scale of Parents Social Support					
Social association support	29.22	7.63	30	10	40
Information support	18.42	4.90	18	6	24
Emotional support	24.66	6.05	24	8	32
Maintenance Support	12.24	3.48	12	4	16
Total	84.54	20.4	84	28	112
Renevew Scale of Parents Social Suppot Satisfaction					
Social association support satisfaction	27.35	7.90	30	10	40
Information support satisfaction	16.87	4.79	18	10	40
Emotional support satisfaction	22.35	6.40	24	6	24
Maintenance support satisfaction	11.29	3.37	12	8	32
Total satisfaction	77.86	21.51	84	28	112
Families Resilience	139.09	30.26	132	53	185
Challenge	62.33	14.68	64	21	85
Self-efficacy	36.21	7.3	30	15	45
Commitment	29.5	7.81	32	8	40
Self-control	11	2.85	12	3	15

The average of 'PSS-10' of the families was 23.64 ± 6.3 (0-40), the average of 'PSS-4' was 9.20 ± 2.53 (6-16), and the average of total 'Perceived Stress Scale' was 32.85 ± 8.7 (0-56). This finding indicates that the mothers and fathers' stress levels were high.

The average 'problem focused coping' of the families was 38.51 ± 6.07 (21-48), the average of 'religious coping' was 7.44 ± 1.14 (2-8), 'instrumental social support' mean was 6.64 ± 1.41, 'planning' mean 6.5 ± 1.47, 'acceptance' means 6.45 ± 1.51 'positive reframing' 6.35 ± 1.52), mean 'emotional social support' 5.14 ± 1.54; the mean of 'emotion focused coping' is 35.91 ± 5.90 (24-54), the average of 'self- distraction' is 5.82 ± 1.54 (2-8), the average of 'venting' is 5.56 ± 2.04, the average of 'quitting other activities' is 4.84 ± 1.71, the average of 'mental disinterest' was 4.81 ± 1.66, 'humorous approach' mean 4.51 ± 12.08, 'denial' mean 4.30 ± 1.98, 'behavioural disinterest' average was 3.51 ± 1.55, and 'substance use' mean was 2.55 ± 1.24. Results indicated that while the most common coping styles of families who have children with autism are religious

coping problem focused coping (38.51) and (7.44), the least used coping style is substance use (2.55).

In the sub-dimensions of the Revised Parental Social Support Scale of the families; 'social togetherness support' mean was detected as 29.22 ± 7.63 (10-40), 'information support' average 18.42 ± 4.9 (6-24), 'emotional support' average 24.66 ± 6.05 (8-32), 'care support' average 12.24 ± 3.48 (4-16), the average of 'revised parent social support scale' was 84.54 ± 20.45 (28-112). Results showed that the social support average of the families is above the average. In the sub-dimensions of the Revised Parental Social Support Satisfaction Scale of the families, 'social togetherness support' mean was detected as 27.35 ± 7.9 (10-40), 'information support' mean was 16.87 ± 4.79 (6-24), 'emotional support' mean was 22.35 ± 6.40 (8 -32), the average of 'care support' was 11.29 ± 3.37 (4-16), and the average of 'revised parental social support satisfaction scale' was 77.86 ± 21.51 (28-112). Results also showed that families are satisfied with social support systems.

Among the family resilience scale sub-dimensions of families; 'combativeness' means has been detected as 62.33 ± 14.68 (21-85), 'self-efficacy' mean is 36.21 ± 7.3 (15-45), 'commitment to life' mean is 29.5 ± 7.81 (8-40), 'self-control mean is 11 ± 2.85 (3-15) and family resilience total means 139.04 ± 30.26 (53-185). Results indicated that the family resilience of the parents of the child with autism is high.

Table 3: Correlation Between Perceived Stress and Sociodemographic Variables, Coping, Social Support and Family Resilience

Variables	1	2	3	4	5	6	7	8	9	10	11
Gender	1										
Education Status	-.346**	1									
Income	-.295**	.518**	1								
Number of Children	158**	-.476**	-.165**	1							
Time of autism noticed	-.131*	-.018	.144*	.092	1						

Family Resilience	-.242**	.270**	.235**	-.215**	-.105	1					
Problem-focused Coping	.040	.145*	.126*	-.166**	-.036	.581**	1				
Emotion-focused Coping	.067	-.116*	-.185**	-.060	.017	.150**	.188*	1			
Social Support	-.035	.088	.127*	-.036	-.076	.246**	.185**	-.080	1		
Social Support Satisfaction	-.074	.072	.072	-0.91	-.029	.341**	.246**	.032	.7631	1	
Perceived Stress	.124*	-.144*	-.194**	.127*	-.148**	-.297**	-.189**	-.073	-.010	-.058	1

The correlations between perceived stress, social support, coping and family resilience levels and sociodemographic variables for parents of child with autism are given in Table 3.

The Pearson correlation coefficients revealed that perceived stress was statistically significantly associated with gender, level of education, monthly income, number of children, noticed age, family resilience and problem-focused coping, indicates that, mother, less educated, unemployed, having more cihldren, lower age to notice autism, lower family resilience and lower problem-focused coping had a higher level of perceived stress.

Table 4: Multiple Hierarchical Regression Analysis on Impacts of Some Demographical Features of Families, Their Coping Levels, Social Support Levels and Family Resilience Levels on Perceived Stress

Variables	**β_1**	**β_2**	**β_3**	**β_4**	**β_5**
Step 1					
Parents' Gender	.05	.06	.06	.06	.00
	.44	.62	.61	.61	.03
Parents' Education	-.01	.00	-.01	-.01	.01
	-.02	.01	-.02	-.02	.02

Parents' Income Level	-.14*	-.12	-.14*	-.14*	-.19
	-.62	-.55	-.61	-.62	-.53
Number of Children	.10	.08	.07	.07	.06
	.52	.41	.37	.37	.32
Time of autism noticed	-.13	-.13*	-.13*	-.13*	-.15
	-.55	-.54	-.56	-.55	-.64
Step 2: Problem-focused Coping		-.16*	-.14*	-.15*	-.01
		-.70	-.62	-.65	-.05
Step 3: Emotion-focused Coping			-.08	.08	-.05
			-.49	-.47	-.33
Step 4: Social support				.03	.07
				.03	.06
Step 5: Family resiliency					-.27**
					-.15
ΔF	4.201**	4.931**	4.526**	3.993**	5.150**
R^2	.067	.092	.098	.099	.138
ΔR^2	.07**	.02*	.01	.00	.04**
****p<.05, **p<.001**					

A five-stage hierarchical multiple regression was performed to analyse the relative effects of sociodemographic and psychosocial characteristics of families of children with autism on their perceived stress levels and test the multiple variables' contributions. Table 4 shows the results of the regression analysis.

As a predictor variable in the first block of multiple hierarchical regression analysis; Parents' gender, parental education level, family income level, number of children and time of autism noticed were entered. The model explained approximately 7 % of the observed variance. The parent's income level (β = -.14 p <.05) contributed significantly to the model.

In the second block, the average scores they got from the Problem-focused Coping subscale were added to the model, and the model explained 9 % of the observed variance. It was determined that the average scores from the Problem-focused Coping subscale significantly contributed to the model (β= -.16, p<.05). The contribution of the added variable to the change in the model (RΔ = .02, p<.05) was significant.

In the third block, the average scores from the Emotion- focused Coping subscale, the model explained 10 % of the observed variance. It was determined that the average scores they got from the Emotion-focused Coping subscale had not made a significant contribution to the

model (β= -.08, p>.05). The contribution of the added variable to the change in the model (RΔ = .01, p>.05) was not significant.

In the fourth block, the average scores from the Revised Parental Social Support Scale were added to the model, and the model explained about 10 % of the total variance. It was determined that the average scores they got from the revised Parental Social Support Scale had not made a significant contribution to the model (β= .03, p>.05). The contribution of the added variable to the change in the model (RΔ = 0, p>.05) was not significant.

In the last block, the average scores from the Family Resiliency Scale were added to the model, and the model explained about 14 % of the observed variance. It was found that the mean scores (β=-.27, p<.001) they got from the Family Resiliency Scale had a significant contribution to the model. It was determined that 4 % (RΔ = .04,<p.001) of the added variable's contribution to the change in the model was significant.

Discussion

This cross-sectional study examined perceived stress levels associated with the following factors: Coping strategies, social support, family resiliency, and sociodemographic factors among 300 families (213 mothers, 87 fathers) of children with autism in a Turkish sample. Results in this cross-sectional study were generally consistent with those of previous studies.

Results showed that the mothers and fathers' stress levels were high. Similar results were also found in a study of Hastings and Johanson (2001) and Seligman and Darling (2007) reported that families with children with autism experience high levels of stress. In this study, mothers' perceived stress levels were higher than fathers. This result is consistent with previous studies. Mothers of children with autism are the most adversely affected by stress-related factors in caring for a disabled child (Boyd, 2002). Studies similarly reveal that Beşikçi (2000) similarly stated in his study that mothers of children with autism have higher stress scores than fathers. Meirsschaut, Roeyers, and Warreyn (2010) found that mothers experienced significantly higher levels of stress in connection with their child with ASD than their child with typical development. In other studies, mothers' stress levels were higher than fathers (Dabrowska & Pisula, 2010: 275; García-López, Sarriá, & Pozo, 2016; Davis & Carter, 2008; Ang & Loh, 2019; Jones, Totsika, Hastings, & Petalas, 2013; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014; Pisula & Pore¸bowicz-D¨orsmann, 2017; Tehee, Honan, & Hevey, 2009; Sabih and Sajid; 2008; Hastings, Kovshoff, Ward, Espinosa, Brown, & Remington, 2005)

Our study also found that as the education level of the families increased, their stress decreased. This result is consistent with a study conducted by Sencar (2007) with mothers of mentally disabled children, it was found that the stress level of mothers of children with autism differed according to the mother's educational status. According to Stanojević, Nenadović, Fatić

and Stokić (2017), parents with lower education experience more significant stress than parents with higher education. Phetrasuwan and Miles (2009) reported that less educated mothers had a higher level of stress.

The findings of this study showed that the gender of the child did not affect the perceived stress of the families. Similarly, Lecavalier et al. (2006) also reported that the child-related factors that most strongly predict families' stress levels is not the child's gender but the child's behavioural problems. When the effect of the gender of the child on the stress level of the families is examined, it is seen that the findings of many studies are consistent with this finding of our study. In the studies conducted by Görgü (2005) and Sencar (2007) with mothers of children with autism, it was observed that the gender of the children did not affect the mothers' stress and depression levels. The reason why the gender of the child does not make a significant difference can be thought of like the fact that the needs of the children or the difficulties they bring to the family do not differ much depending on whether they are a girl or a boy.

Results showed that the most common coping styles of families who have children with autism are religious coping and problem focused coping. In the study, in which the strategies used by families with disabled children to cope with stress were investigated, it was stated that the most used method was problem focused coping. It was determined that mothers used problem-centered coping more than fathers. (Glidden, Billings, & Jobe, 2006). In other studies, it has been stated that problem-focused coping is mostly used to cope with stress (Yurdakul, etc., 2002; Phelps, etc., 2009; Meadon and Stoner, 2010). Hastings, et al. (2005) reported that families of children with autism who use problem-focused coping have higher levels of well-being than those who use emotion-focused coping. The extent to which parents with autistic children cope with the processes they experience is related to social support mechanisms (Arslan, 2020). Also, the social support average of the families is above the average. Support systems play an important role in parents' ability to cope and manage the stressors when having a child with autism (Hartman, 2012).

The findings of this study showed that the stress decreases as resilience increases in families. In the study, which analyzed 28 articles on stress and resilience in parents of children with autism, six main factors associated with parenting stress were pointed out. These are listed as social support, severity of autism symptoms, financial difficulties, parents' perception and understanding of autism, parents' concerns about their children's future, and religious beliefs (Bekhet, Johnson, & Zauszniewski, 2012). Türkan (2017) found a negative relationship between psychological resilience and parental stress in her study on stress.

Conclusion

As a result of the study, perceived stress levels of the families who have children with autism was high. While the most common coping style used by families with children with autism is religious and problem focused coping, the least common is substance use. It was determined that the social support systems of the families were above the average, and they mostly used social togetherness support. It was found that families were satisfied with their social support system and family resilience was high. The stress experienced by mothers was higher than that of fathers. Mothers and fathers' coping methods differ; while mothers use emotional, social support, religious coping, and focus and express emotions; fathers prefer planning and denial. At the end of the study, parents', income level, time of autism noticed, problem-focused coping methods and family resiliency negatively affects family stress.

Limitations

The research has some limitations. First of all, many Special Education and Rehabilitation Centers serving children with autism in Ankara were contacted. However, institutional permissions could not be received for many of them. As a justification, it has been argued that the families are overexposed to such studies, that there is no development for the benefit of the family at the end of the studies and that the families are tired of these. Secondly, the target quantity of the study is 300 individuals, including 150 mothers and 150 fathers. However, the target number of fathers could not be reached since fathers are at work during the week-time hours. The mothers are generally responsible for child care at the weekend. Then it is difficult to reach the fathers through mothers, so the study was limited to 87 fathers. At this point, the number of participants in the study changed to 213 mothers and 87 fathers. Thirdly, the results of the research are valid for Turkish cases. Therefore, while the results of this study can be generalised to Turkish culture, they should be repeated based on samples taken from other cultures for comparison.

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