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RESEARCH ARTICLE

Burnout, Anxiety and Coping Attitudes in Parents of Children with Autism Spectrum Disorder

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Abstract

Objective: In this study, the relationship between burnout level, anxiety and coping attitudes of parents with children diagnosed with autism spectrum disorder (ASD) was examined together with demographic variables. **Methods:** Relational model was used in the research. The research was conducted with the parents of 180 children diagnosed with ASD. Data were obtained using the Beck Anxiety Inventory (BAI), Maslach Burnout Inventory (MBI), and the Coping Attitudes Rating Scale (COPE). T Test, One Way Analysis of Variance (ANOVA) and Pearson correlation analysis were used in the analysis of the data. **Results:** In the research findings, it was observed that the burnout level of the parents differed according to the age groups of the autistic children, the number of siblings and the psychiatric disease history of the parents. In addition, it was observed that the anxiety level and coping methods of the parents differed significantly according to the psychiatric illness history of the parents. A strong positive correlation was found between parents' anxiety and burnout levels. A moderate positive relationship was also found between the emotional burnout levels of the parents and their coping levels. **Conclusion:** It was observed that the levels of anxiety and burnout were lower in parents who used the problem-focused coping method. In addition, it has been observed that parents overcome problems by using problem-focused coping methods and this situation affects their lives positively. In addition, it was observed that parents with high levels of anxiety and burnout used dysfunctional coping methods more.

Keywords

Autism Spectrum Disorder, Diagnosis, Parents, Anxiety, Burnout, Coping, Attitude

INTRODUCTION

When every family receives the news of a new born baby, they begin to dream on the basis that the baby will be perfect. However, the birth of a baby with a disability or the emergence of disability in the child in the following years cause the dreams of parents about their children to be destroyed (Varol, 2005) and the existing order in the family to change. In the new arrangement made according to the disabled child, the roles of the parents also change, a troublesome process begins and the parents face many difficulties (Dicle, 2012). Providing care for a child with a disability is a frustrating situation, but it also

causes emotional, financial and social difficulties for parents (Dereli and Okur, 2008). Disorder (ASD) is a lifelong developmental disorder that affects not only the individual but also the family. When a child is diagnosed with ASD, parents experience a tremendous sense of loss. The assumption that they are raising a "normal child" is no longer a reality (Norton and Drew, 1994).

Compared to the normally developing child, many behaviours of the child with ASD related to the features of autism cause constant stress to the family and may threaten the general health of the family (Lecavalier et al., 2006). Delays in social and language development, health problems (frequent illness, allergies, etc.), inability to play

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games like their peers, or sleep problems (sleeping in the same bed with their parents, going to bed late) are just a few of these behavioural patterns. Due to socialization and communication problems that may arise from various reasons with the environment (Roxane and Carmen, 2020), having a child with ASD, especially for mothers who are usually in the leading role in child care, causes them to take on much more responsibility and therefore a sense of helplessness, increased anxiety level and stress (Dale et al., 2006). In addition, it is stated that the children of mothers with OSD children are exposed to more stress since they cannot control their children's behaviors despite their physical and mental development (Cahit et.al., 2018).

Just as every child with ASD is unique, each parent's response to a diagnosis of ASD is also unique. However, many parents whose child is diagnosed with a developmental delay are worried about their children and their own lives because they do not have full information about the changes that the diagnosis will cause. The basis of these concerns is the fear of the families against the unknown and uncertain (Üstüner Top, 2009). Mothers with disabled children have stated that their children's dependence on them causes more stress (Uğuz et al., 2004). Although parents know that every child has the right to education, they are aware that the child with ASD does not even have the opportunity to receive distance education without going to a special education institution, and for these reasons, they have a large share in the care of their children (Stambekova et al., 2021). In addition, the presence of additional health problems in the child who needs special care causes parents to experience more stress (Batu, 2011).

Studies show that the disability level of the child with ASD is related to the mother's level of depression, hopelessness and burnout (Benson and Karlof, 2009; Falk et al., 2014; Firth and Dryer, 2013; Kim et al., 2016; Machado et al.,2016). Şengül and Baykan (2012) stated that there is an increase in mothers' rates of, been diagnosed with depression and anxiety disorders in proportion to the decrease in the intelligence level of children. Montes and Halterman (2007) similarly state that the severity of ASD symptoms and the behavioural characteristics of the child are strongly related to parenting stress. A mother with a disabled child may experience constant anxiety about whether or

not her child will be able to lead a life alone due to uncertainties about the future of the child and especially if she is unable to care for the child or she dies (Üstüner Top, 2009). It has been stated that it is also related to the child's level of the problem behaviour, level of alienation from social life, dependence on the caregiver throughout his life, anxiety level and financial problems of the family (Benderix et al., 2006; Benson, 2006; Montes and Halterman, 2007).

Although difficulties may occur in the care of the child with developmental delay, developing appropriate coping attitudes can play a role in protecting parents from the consequences of negative situations (Essex et al., 1999; Seltzer et al., 1995). Hasting et al. (2005) stated that the use of problem-focused coping styles by parents of children with ASD enabled them to have a higher level of well-being compared to those who used emotion-focused coping (Hasting et al., 2005). On the other hand, Gona et al. (2016) states that emotional coping with faith or prayer is a prominent approach in some cultures, such as Africa, and parents find solace in the belief that the presence of a child with autism in the family is planned by God.

The effects of having a child with ASD on parents and other family members are as versatile as ASD itself. Raising a child diagnosed with ASD is difficult due to the possible aggression, inattention and impulsivity they may display (Kaminski et al., 2008). It takes a lot of time, effort and patience to meet the high care demands of children with ASD (Vohra et al., 2014). However, parents of children with ASD face high financial burden such as heavy health expenditures, unemployment or job loss (Cidav et al., 2012; Lee et al., 2008). Today, the most important research question about children with ASD revolves around the identification of factors that may contribute to reducing the stress and burden on these families (Hayes and Watson, 2013).

OSD, which is the most common of the pervasive developmental disorders and therefore attracting the attention of researchers, is a long-studied area in the literature. When the studies in this area are examined, it is noteworthy that the concepts of depression, stress, anxiety and coping strategies are frequently studied, especially in parents and teachers with whom the child with OSD is in contact (Al-Oran and Al-Sagarat, 2016; Acar and Karaaslan, 2022; Agyapong et al., 2022;

Al-Farsi et.al, 2016; Ang and Loh, 2019). When studies involving the concept of OSD and burnout are examined, it is particularly striking that teachers are addressed (Aydemir et. al., 2014; Cahit et. al., 2017; Park and Shin, 2020; Sarıçam & Chios, 2014). However, apart from the difficult educational processes of these children, it was thought that it would be very likely that the diagnosis of OSD could be made at an early age and that their families would experience burnout in the process of caring for the child financially and morally. Anxiety, burnout and coping strategies were discussed together in this study, since it is thought that burnout is not only a concept specific to the field of education, but that parents as well as teachers can feel burnout as much as they can feel anxiety in this process

As in this study, comprehensive knowledge of these factors will facilitate the development of more targeted interventions to assist families. It is thought that with the support given to parents of children with autism, the level of anxiety and burnout will decrease and their negative effects on both other family members and their work lives will be minimized. It is foreseen that the study will also help to identify the deficiencies in the field and to obtain data that will contribute to the realization of new research. Therefore, this study aimed to determine the burnout levels, anxiety and coping attitudes of parents of children with ASD according to some demographic variables as well as the relationship between the variables. In accordance with this aim, answers to the following questions were sought in the study:

- Do the anxiety, burnout levels and coping approaches of parents with an ASD child differ according to the age of the child, the number of siblings and birth order?
- Do the anxiety, burnout levels and coping approaches of parents with children with ASD differ depending on whether the parents have a psychiatric history or not?

Is there a significant relationship between the anxiety levels, burnout levels and coping approaches of parents who have children with ASD?

MATERIALS AND METHODS

Research Model

In this study, it was aimed to examine the anxiety, burnout and coping approaches of parents

who have children with ASD. For this reason, the correlational model, one of the quantitative research methods, was used. This model is a research model conducted to determine the relationship and change between two or more variables (Senthilnathan, 2017). Ethical permission for the study was approved by the Near East University Social Sciences Ethics Committee with the licenced no YDÜ/SB/2018/319. Before the study, the consent form was read to the participants, the voluntary basis was stated and signed.

Sample

It was sought for the parents to have a child between the ages of 3-18 and the child to be diagnosed with ASD according to the DSM-V diagnostic criteria. For this reason, it was selected by the criterion sampling method, which is one of the sampling types for sampling purposes. In the criterion sampling method, the sample is formed from people with the characteristics determined on the subject (Büyüköztürk et al., 2022). The sample of the study is a total of 180 parents of children with ASD who attend Special Education and Rehabilitation Centers in Izmir. General information about the children participating in the study is given in Table 1, and descriptive information about the parents is given in Table 2.

Data Collection Tools

Research scales were applied to the parents who voluntarily participated in the study and signed the consent form. In the study, Beck Anxiety Inventory was used to obtain parents' anxiety level data, Maslach Burnout Inventory to obtain burnout data, and Coping Strategies Form to obtain coping attitude data. In addition, a Personal information form was applied to obtain more information about the child diagnosed with ASD and their parents.

Beck Anxiety Inventory (BAI)

This scale, developed by Beck et al. in 1988 and developed to measure the level of anxiety, consists of 21 items. Each item is graded between 0 and 3 points. In this scale, 8 to 15 points indicate mild anxiety, 16 to 25 points moderate anxiety, and 26 to 63 points indicate severe anxiety. The adaptation study of the scale to Turkish culture was carried out by Ulusoy et al. (1998), and it was determined that the Cronbach Alpha reliability coefficient was "0.93" and the test-retest reliability coefficient was "0.57". Item and score correlations are between "0.45" and "0.72" values (Ulusoy et

al., 1998). In this study, the Cronbach's Alpha reliability coefficient of the scale was found to be 0.93 in the statistical analysis of the 21-item BAI

reliability applied to the parents. This value indicates that the scale was applied within the limits of reliability.

Table 1. Distribution of general information about the children participating in the study

	n	%		n	%	
Age			Diagnosed age			
3-6 age	63	35	Until 3	118	65.6	
7-11 age	92	51.1	Between 4-6	54	30	
12-18 age	25	13.9	After 7	8	4.4	
Sibling			Additional diagnostic			
None	50	27.8	Yes	50	27.8	
1-2	117	65	None	130	72.2	
3andabove	13	7.2				
Birth order			Duration of special education			
First	100	55.6	0-2 years	66	36.7	
Middle	35	19.4	3-5 years	60	33.3	
Last	45	25	More than 6 years 54		30	

Table 2. Distribution of parents' relevant general information

	n	%
Age		
20-30 age	21	11.7
31-40 age	100	55.6
Above 41	59	32.8
Gender		
Women	156	86.7
Men	24	13.3
History of psychiatric		
illness		
Yes	15	8.3
None	165	91.7

Maslach Burnout Inventory (MBI)

The scale developed by Maslach and Jackson (1981) to determine the level of burnout in mothers of mentally retarded children consists of 22 items and 3 sub-dimensions (emotional exhaustion (9), depersonalization (8) and lack of personal achievement (5). The coefficient was determined as 0.93 (Maslach and Jackson, 1981) The first adaptation of MBI to Turkish culture was carried out by Ergin (1992). It has been determined that it contains two factors, namely, personal success. It has been determined that the items belonging to the 'Depersonalization' factor belong to the 'emotional burnout' dimension (Duygun and Sezgin, 2003).

When the reliability analysis of the 22-item MBI Scale applied to the parents in this study was evaluated, it was determined that the Cronbach's Alpha Value was 0.767. The Cronbach's Alpha

Value for the emotional burnout sub-dimension of the scale was 0.863, and the Cronbach's Alpha Value for the personal achievement sub-dimension was 0.768. Cronbach's Alpha Values obtained in terms of both the overall scale and the sub-dimensions of Emotional Burnout and Personal Achievement indicate that the scale was applied within the limits of reliability.

Coping Attitudes Evaluation Scale (COPE)

The scale developed by Carver et al. in 1989 was adapted to Turkish culture by Ağargün et al. in 2005. With this scale, it is aimed to evaluate the reaction of individuals when they encounter difficult or overwhelming situations or problems in their daily lives. The scale is in the form of a selfreport and consists of 60 questions and 15 subdimensions. Active coping, planning, suppression of other occupations, holding back, use of useful social support subscales is classified as problemfocused coping. The use of emotional social support, positive reinterpretation and development, acceptance, joking, and religious coping subscales are defined as emotion-focused coping. Focusing on the problem and revealing emotions, behavioral disengagement, substance use, denial, and mental disengagement subscales is expressed as the least useful dysfunctional coping attitude.

In this study, Cronbach's Alpha Value was calculated as .89. The Cronbach's Alpha Value for the "Problem-focused coping" sub-dimension of the scale was determined as .92, the Cronbach's

Alpha Value for the "Emotion-focused coping" sub-dimension was .76, and the Cronbach's Alpha Value for the "Dysfunctional coping" sub-dimension was determined as .85.

Personal Information Form

In the form developed by the researcher, there are 9 open-ended questions about socio-demographic information about the child with ASD and parents.

Data Collection

The research data were collected from the parents of individuals with ASD between the ages of 3 and 18, who were registered in the Special Education and Rehabilitation Centers in the Buca district of İzmir. Three centers gave permission for data collection. Before the scales were applied in the center, the families were informed about the study and the scales, and the families who wanted to participate voluntarily signed the consent form and the data were collected. Due to the large number of scale items, the applications were made face-to-face with the parents, 2 days a week.

Statistical Analysis

IBM SPSS 24.0 package program was used for data analysis. First of all, the conformity with the data to the normal distribution was determined by the skewness and kurtosis values. The skewness and kurtosis values between +1.5 and -1.5 indicate that the data are normally distributed (Tabachnik

and Fidell, 2013). It was determined that the skewness and kurtosis values of the study data were distributed between +1.5 and -1.5 and were in accordance with the normal distribution at the 5% significance level. For this reason, T Test, which is one of the parametric analysis methods, was used in the analysis of the data consisting of two groups. One-way Analysis of Variance (Anova) and Bonferroni multiple comparison analysis were used to compare measurements of more than two groups. Pearson correlation test was applied for parent burnout, anxiety and coping attitudes.

RESULTS

In the light of the demographic information obtained from the participants, there was no significant difference between the parents' anxiety, burnout and coping attitudes depending on the gender of the child, the age group at which he was diagnosed, the status of being diagnosed with an additional disease and the duration of special education. In addition, no significant difference was found, according to the age group, education level, employment status or monthly income of the parents (p>.05). Demographic variables that make a significant difference are indicated in the tables below.

Table 3. ANOVA results according to the age groups of children

Scales	Sub- dimensio ns	Source of Variance	bs uns	df	Mean Sq	F	p
	_	Btw	412.387	2	206.193	1.597	.205
BAI		Wth	22859.6	177	129.15		
	Emotional burnout	Btw	744.686	2	372.343	3.244	.041*
31		Wth	20318.3	177	114.793		
MBI	Personal success	Btw	87.31	2	43.655	1.312	.272
		Wth	5889.89	177	33.276		
	Problem-foc. cop.	Btw	312.612	2	156.306	1.504	.225
		Wth	18394.6	177	103.924		
PE	Emotional focus. cop.	Btw	11.448	2	5.724	0.024	.976
COPE		Wth	41603	177	235.045		
	Dysfunctional cop.	Btw	239.216	2	119.608	1.244	.291
		Wth	17021.7	177	96.168		

When the anxiety, burnout and coping attitudes of the parents according to the age status

of the children were compared with the one-way analysis of variance (ANOVA) for the unrelated

sample, a a statistically significant difference was found between the groups in the emotional burnout sub-dimension of the MBI according to the age of the children [F(2-177) =3.24, p \le . 05, eta squared (η 2) = 0.03]. As a result of the Bonferroni multiple

comparison analysis emotional burnout levels of parents with 7-11 years old children ($\overline{X}_{7-11years}$ =34.93) with ASD were found higher than those with 12-15 years old children ($\overline{X}_{12-18years}$ =30.36).

Table 4. ANOVA results according to the number of the siblings

50	ısio	e of	Sq		Sq		
Scales	Sub- dimensio ns	Source of Variance	Sum	J B	Mean	F	p
		Btw	58.037	2	29.019	0.221	.802
BAI		Wth	23213.94	177	131.152		
	Emotional burnout	Btw	122.463	2	61.231	0.518	.597
81		Wth	20940.52	177	118.308		
MBI	Personal success	Btw	243.52	2	121.76	3.759	.025*
		Wth	5733.68	177	32.394		
	Problem-foc. Cop.	Btw	247.143	2	123.572	1.185	.308
		Wth	18460.1	177	104.294		
PE	Emotional focus. Cop.	Btw	1178.541	2	589.27	2.579	.079
COPE		Wth	40435.9	177	228.451		
	Dysfunctional cop.	Btw	11.497	2	5.749	.059	.943
		Wth	17249.45	177	97.455		

As can be seen in Table 4, when the anxiety, burnout, and coping attitudes of the parents according to the number of siblings of the children were compared with the ANOVA analysis, a significant difference was found between the groups in the personal achievement

sub-dimension of the MBI [F(2-177)=3.75, p \leq .05, eta squared (η 2)= 0.04]. As a result of the Bonferroni multiple comparison analysis the personal achievement levels of the children with no siblings (\bar{X}_{none} =35.92) were found to be higher than those with 3 or more siblings ($\bar{X}_{3-above}$ =31.69).

Table 5. ANOVA results according to the birth order

Scales	Sub- dimens ions	Source of Varian ce	Sq	df	Mean Sq	F	p
I		Btw	114.357	2	57.178	0.437	.647
BAI		Wth	23157.621	177	130.834		
	Emotional burnout	Btw	231.896	2	115.948	0.985	.375
MBI		Wth	20831.081	177	117.69		
M	Personal success	Btw	14.714	2	7.357	0.218	.804
		Wth	5962.486	177	33.686		
	Problem-foc. cop.	Btw	218.769	2	109.384	1.047	.353
		Wth	18488.476	177	104.455		
COPE	Emotional focus. cop.	Btw	1103.852	2	551.926	2.411	.093
ဥ		Wth	40510.593	177	228.873		
	Dysfunctional cop.	Btw	814.817	2	407.409	4.385	.014*
		Wth	16446.133	177	92.916		

As can be seen in Table 5, a statistically significant difference was found between the groups as a result of the ANOVA analysis in the dysfunctional coping sub-dimension of the COPE scale according to the birth of the ASD child [F(2-177)=4.38, $p \le .05$, eta squared ($\eta 2$)= 0.04]. As a

result of the Bonferroni multiple comparison analysis the last child (\overline{X}_{last} =39.93) uses dysfunctional coping strategies more than the first child (\overline{X}_{first} =35.39) and median child (\overline{X}_{median} =34.31) groups.

Table 6. T-Test results of scale scores according to the psychiatric illness history of the parents

Scales	Sub- dimensions	Psychiat ric illness Z		\overline{X}	SS	sd	t	р
BAI		Yes	15	44.07	17.08			
M		None	165	33.10	10.34	178	3.691	.000*
	Emotional burnout	Yes	15	37.40	15.67			
MBI		None	165	27.68	9.98	178	3.421	.001*
Z	Personal success	Yes	15	31.80	7.06			
		None	165	34.49	5.62	178	1.736	.084
	Problem-foc. cop.	Yes	15	59.60	12.51			
		None	165	63.04	9.99	178	1.251	.213
PE	Emotional focus. cop.	Yes	15	48.00	18.80			
COPE		None	165	48.61	14.95	178	0.147	.883
	Dysfunctional cop.	Yes	15	44.73	13.27			
		None	165	35.55	9.12	178	3.58	.000*

Table 6 shows the results of the t-test for unrelated samples, which were conducted to determine whether the parents' history of psychiatric illness had a significant effect on anxiety, burnout, and coping attitudes. Accordingly, the anxiety level is found higher in the parents with a history of psychiatric illness (\bar{X}_{yes} =44.07) than the without psychiatric illness group (\bar{X}_{no} =33.10) [t(178)=3.69, p≤.05]. At the

same time, emotional burnout found higher in the parents with a history of psychiatric illness (\bar{X}_{yes} =37.40) than the without psychiatric illness group (\bar{X}_{no} =27.68) [t(178)=3.42, p≤.05]. And lastly dysfunctional coping strategies usage found higher in the parents with a history of psychiatric illness (\bar{X}_{yes} =44.73) than the without psychiatric illness group (\bar{X}_{no} =35.55) [t(178)=3.58, p≤.05].

Table 7. Correlation analysis

			M	BI		COPE	
			Emotional	Personal	Problem-foc.	Emotional foc.	Dysfunctional
			burnout	success	cop.	cop.	cop.
BAI		r	.688**	197**	158*	-0.007	.329**
		p	.000	0.008	0.034	0.930	.000
	Emotional burnout	r		185*	185*	-0.005	.425**
		p		0.013	0.013	0.950	.000
MBI	Personal success	r			.356**	-0.041	-0.119
		p			.000	0.585	0.113
	Problem-foc. Cop.	r				.179*	0.034
		p				0.016	0.655
COPE	Emotional focus. Cop.	r					.252**
	-	p					0,001

As seen in Table 7, the relationship between anxiety, burnout, and the scores they got from coping attitudes was evaluated with the Pearson Correlation test. According to the table, while there is a positive and significant relationship between parents' anxiety scores and the emotional burnout sub-dimension of the MBI (r=0.68, $p \le .05$), there is a negative and significant relationship between them and the personal achievement sub-dimension (r=0.19, p). ≤.05). On the other hand, there was a negative and significant relationship between parents' anxiety scores and the problem-focused coping sub-dimension of the COPE (r=0.15, $p \le .05$), while a positive and significant relationship was found between the dysfunctional coping sub-dimension. (r=0.32, $p \le .05$).

A statistically negative and significant relationship was found between the two sub-dimensions of the MBI (r=0.18, p \le .05). While there was a negative and significant relationship between the emotional burnout sub-dimension of the MBI and the problem-solving sub-dimension of the COPE coping attitude scale (r=0.18, p \le .05), a positive and significant relationship was found between the dysfunctional coping sub-dimension. (r=0.42, p \le .05). A positive and significant relationship was also found between the personal achievement sub-dimension of the MBI and the problem-solving sub-dimension of the COPE coping attitude scale (r=0.35, p \le .05).

While there was a statistically positive and significant correlation between problem-focused coping sub-dimension and emotion-focused coping sub-dimension of COPE coping attitude scale (r=0.17, p \leq .05), emotion-focused coping sub-dimension and dysfunctional coping A positive and significant correlation was found between the sub-dimensions (r=0.25, p \leq .05).

DISCUSSION

In this study, it was aimed to investigate whether burnout, anxiety and coping attitudes of parents with autistic children differ depending on the age of the child, the number of siblings, the age of the autistic child, and whether the parent has a history of psychological illness. The study also aimed to determine the relationship between coping attitudes, burnout level and anxiety. According to the results obtained, it was determined that the approaches of mothers and

fathers to cope with anxiety and burnout levels differ in varying proportions according to some of the socio-demographic characteristics.

Socio-demografic characteristics and variables relations

After the diagnosis of autism, parents face the loss of expectations of having a child with normal development, and this causes them to face uncertainties not only about the future of the child but also about the future of the family (Dale, Jahoda et al., Knott, 2006; Poslawsky, Naber, Van Daalen, and Van Engeland, 2013). In the study, emotional burnout levels of parents with autistic children in the 7-11 age group were found to be higher than those in the 12-18 age group. Similarly, parents with autistic children in the 7-11 age group were found to have higher anxiety levels, although it was not statistically significant. These results show that in families with a child diagnosed with ASD in the 7-11 age group, the anxiety about the future of the child is the highest, and as the acceptance of the disease increases, both the level of anxiety and emotional burnout decrease over time. In the literature it is also shown that diagnosing a child allows parents to cope with this diagnosis and eliminates the guilt associated with attributing the child's behaviour to bad parenting (Mulligan, MacCulloch, Good, and Nicholas, 2012). In addition, parents focus on what they can do for the child as a parent after accepting the diagnosis and the child as it is (Woodgate, Ateah, and Secco, 2008; Dale, Jahoda, and Knott, 2006).

Akarsu & Akgün Kostak (2021) stated that with the increase in the number of children, the responsibility of the mother increases and this may reflect on burnout. Consistent with their study, although the difference was not found to be significant, the level of emotional exhaustion was determined at most in parents with three or more children. In addition, in this study, dysfunctional coping methods were mostly seen in these parents. Based on this result, it can be argued that the parents participating in the study could not develop effective coping strategies due to higher emotional burnout.

Mothers with children with ASD report that their relationships with their children, especially those who do not have a diagnosis of ASD, are of lower quality and inefficient (Nealy, O'Hare, Powers, and Swick 2012). The reason for this situation is that they do not spare enough time for

the normally developing child, do not plan out-of-home social activities for the child, and force the child to grow faster than he or she is ready (Nealy et al, 2012). Consistent with these findings in the literature, in this study, although not at the level of significance, the lowest anxiety level was found only in single-child mothers with children with ASD. In addition, the level of personal achievement was found to be higher in this group of mothers compared to other groups. The fact that the level of anxiety was found to be higher in mothers with more children can be explained by the anxiety of these mothers because they do not spare enough attention and time to their other children, and their anxiety levels increase.

Having a child with ASD leads to either improvement or deterioration in spouse and extended family relationships. In families with a good marital relationship, it is expected that the spouses support each other both emotionally and in daily life for the care of the child, but it is also accepted as an important coping method. It has been observed that receiving support from the extended family in both emotional and daily life is also valuable for parents. The benefits of having family support are supported by the relationship with increased family support with decreased parental stress level and increased psychological well-being found in studies in the literature (Benson and Kersh, 2011; Hartley, Barker, Baker, Seltzer, and Greenberg, 2012). In another study conducted with mothers who have a child with ASD, it was found that with the support provided by grandparents or individuals/organizations that provide special education support, mothers got rid of daily problems and their behavioral problems decreased (Dyches et al., 2016). On the other hand, mothers who describe the worsening of spousal relations attribute this to both the tendency of spouses to blame each other due to the diagnosis, the time and energy they cannot spare for each other for the needs of the child with ASD, and more importantly, the lack of support provided by the fathers in this process (Ooi, Ong, Jacob. and Khan, 2016).

Psychiatric disease history and the variables relations

It has been determined that parents who have a child with autism have increased stress levels or more psychiatric diseases than other families with a disabled or normally developing child. (Estes, Munson, Dawson, Koehler, Zhou, and Abbott, 2009; Ou, Cha, and Wang, 2010). In the literature, it is stated that mothers who are responsible for the care of disabled children are more exposed to stress and their psychological and physical health deteriorates compared to mothers with normally developing children without diagnosis (Lyons, Leon, RoeckerPhelps, and Dunleavy, 2010; Davis and Carter, 2008). In this study, a history of psychiatric illness was seen among the parents at a rate of up to 10%. This rate is very close to Sahin's (2017) rate of psychiatric illness found in mothers with children with ASD and specific learning difficulties. In addition, it was observed in the study that the level of anxiety and emotional burnout was higher in mothers with a history of psychiatric illness. Supporting this finding, Candir (2015) found that most of the parents with children with ASD and Down Syndrome had a history of psychiatric treatment. In this study, it was observed that parents with psychiatric illness dysfunctional predominantly used strategies. Dysfunctional coping strategies play a role in the relationship between stressors and mental disorders (Çandır, 2015).

The variables relations

When the relationship between anxiety and burnout levels and coping approaches of parents who have a child with ASD was examined, it was seen that there was a relationship between parents' anxiety, burnout levels and coping approaches in different directions and at different rates. In the study, emotional burnout levels of parents with high levels of anxiety were also found to be high. On the other hand, it was revealed that the anxiety levels of parents with high personal achievement levels were low. This finding is compatible with Tahincioğlu's (2016) study. According to the anxiety accompanies literature, 15-54% psychological disorders in parents with a child with ASD (Hastings and Brown, 2002). When a child is diagnosed with autism, it is necessary to find suitable learning centres, which can be costly so that appropriate behavioural intervention can be performed. At this point, insufficient monthly income of the family may also cause an increase in the anxiety and emotional burnout levels of the parents (Tenerife et al., 2022). Bumin et al. (2008) determined that the depression and anxiety levels of parents with children with special needs were in the dimension of psychological support, but necessity, so this situation had negative effects on their quality of life. In addition, the chronic nature

of autism spectrum disorder negatively affects parents and exposes them to the risk of pessimism and burnout (Bristol, 1984; cited in Sivberg, 2002).

As the emotional burnout levels of parents increase, their depersonalization towards having a child with ASD will increase and they will try to cope with the situation by using dysfunctional coping methods. Emotional burnout in parents is an expected result due to the behavior and communication problems that are common in children with ASD (Darica et al., 2000). The reason for this is that parents have various expectations for their children and if these expectations are not met, they go into emotional depression. This negative situation may lead parents to become desensitized to their children's problems, to see themselves as unsuccessful, and to use dysfunctional coping methods.

Approaches to working with parents who have a child with ASD have changed significantly over the past two decades. Marcus, Kunce, and Schopler (1997) pointed out that there is a link between this change and the recognition of ASD as a developmental disorder rather than an emotional disorder. As part of this shift, parents have become more directly involved in their children's treatment (Harris, 1994). Parents are no longer seen as the cause of their child's problem, but are instead identified as partners in their child's treatment. Parents need functional coping strategies to achieve this new role (Sivberg, 2002).

As the number of children diagnosed with ASD increases all over the world, parents of a child with ASD should be provided with resources to support their use of helpful coping strategies that will help their particular situation and reduce their anxiety and stress levels (Hall and Graff, 2012). Işıkhan (2005) stated that adequate coping resources can reduce the effect of factors that cause potential stress. Problem-focused coping methods are generally used in the presence of positive expectations (Durukan et al., 2010). In this study, in accordance with Işıkhan (2005) and Durukan et al. (2010), it was observed that the levels of anxiety and emotional burnout, which were positively related to each other, were lower in parents who used problem-focused coping. In addition, it was observed that my parents with high levels of anxiety and emotional exhaustion used dysfunctional coping methods more. In parallel with the findings of the study, Işıkhan (2005) stated that when compared to other parents, parents who experienced a great deal of distress used less problem-focused coping methods.

Conclusion and Suggestions

The results of the study reveal once again that ASD affects the whole family and family relationships. For this reason, it is extremely important to address the problems of parents and to give them all the support they need. On the other hand, the development of functional coping skills of parents will contribute to their having sufficient strength in their struggle with this difficult situation. At this point, parents' realizing that their own health is important for them to take better care of their children will cause their anxiety and emotional burnout levels to decrease.

The data obtained in this study are especially important in terms of examining psychological symptoms in terms of effectively exhibiting the necessary psychosocial approaches to parents with a child with ASD. However, in order to test the validity of the data, it is recommended that this study be tested in a larger sample group, including other family members. Another suggestion for future research is to investigate which of the functional coping strategies used by parents of autistic children helps to reduce the level of anxiety more. In addition, studies that can be done by evaluating more factors will help to determine the causes of the problems.

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Conflict of interest

No conflict of interest is declared by the authors. In addition, no financial support was received.

Ethics Committee

(Date: 10.12.2018; Decision/ Protocol number: YDÜ/SB/2018/319). Participants who volunteered for the study were informed with a written informed consent form.

Author Contributions

Study Design, EU, GK; Data Collection, GK; Statistical Analysis, EU; Data Interpretation, EU; Manuscript Preparation, EU; Literature Search, EU, GK. All authors have read and agreed to the published version of the manuscript.

REFERENCES

Agyapong, B., Obuobi-Donkor, G., Burback, L., & Wei, Y. (2022). Stress, burnout, anxiety and

- depression among teachers: A scoping review. International Journal of Environmental Research Public Health, 19, 10706.
- Ağargün, M. Y., Beşiroğlu, L., Kıran, Ü. K., Özer, Ö. A., & Kara, H. (2005). Coping Attitudes Evaluation Scale: A preliminary study on psychometric properties, *Anatolian Journal of Psychiatry*, 6, 221-226.
- Akarsu, Ö., & Akgün Kostak M. (2021). Family burden and self-care skills of children with intellectual disability, life satisfaction of their mothers and the effective factors. *International Anatolia Academic Online Journal*, 8(2), 18-35
- Al-Farsi, O., Al-Farsi, Y., Al-Sharbati, M., & Al-Adawi, S. (2016) Stress, anxiety, and depression among parents of children with autism spectrum disorder in Oman: A casecontrol study. *Neuropsychiatric Disease Treatment*, 12, 1943-1951.
- Al-Oran, H. M., & Al-Sagarat, A. Y. (2016). Parenting stress of children with autistic disorder. *Open Access Library Journal*, *3*(7), 1–10.
- Ang, K. Q. P., & Loh, P. R. (2019). Mental health and coping in parents of children with autism spectrum disorder (ASD) in Singapore: An examination of gender role in caring. *Journal of Autism and Developmental Disorders*, 49(5), 2129–2145.
- Aydemir, H., Diken, İ. H., Yıkmış, A., Aksoy, V., & Özokçu, O. (2014). examination of burnout levels and life satisfaction of teachers working in the field of special education. Abant İzzet Baysal University Journal of the Faculty of Education, 15(Special Issue), 68-86
- Batu, E. S. (2011). *Children Aged 0-6 with Down Syndrome and Their Development*, Kök Yayıncılık. ISBN: 9789754994957
- Beck, A. T., Epstein, N., Brown, G., & Steer, R. A. (1988). An inventory for measuring clinical anxiety: Psychometric properties. *Journal of Consulting and Clinical Psychology*, 56(6), 893-897.
- Benderix, Y., Nordstrom, B., & Sivberg, B. (2006). Parents' experience of having a child with autism and learning disabilities living in a group home: A case study. *Autism*, 10(6), 629-640.

- Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stres proliferation. *Journal of Autism and Developmental Disorders*, *36*, 685-695.
- Benson, P. R., & Karlof, K.L. (2009). Anger, stres proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders*, 39, 350-362.
- Benson, P. R., & Kersh, J. (2011). Marital quality and psychological adjustment among mothers of children with ASD: cross-sectional and longitudinal relationships. *Journal of Autism and Developmental Disorders*, 41(12), 1675-1685.
- Bumin, G. T., Günal, A. T., & Tükel, Ş. T. (2008). Anxiety, depression and quality of life in mothers of disabled children. Süleyman Demirel Üniversitesi Tıp Fakültesi Dergisi, 15(1), 6-11.
- Büyüköztürk, Ş., Kılıç, E., Akgün, Ö. E., Karadeniz, Ş., & Demirel, F. (2022). Scientific Research Methods, Pegem Yayınevi. ISBN 978-9944-919-28-9
- Cahit, N., Sakallı Demirok, M., & Direktör, C. (2017). determination of self-efficacy and burnout state of teachers working in the special education field in terms of different variables. *Journal of Education and Training Studies*, 5 (3), 160-166.
- Cahit, N., & Tezer, M., (2018). The relationship between burnout and psychological resiliency levels of special education teachers in a developing economy. Quality and Quantity, 52(2), 1305-1317.
- Carver, C. S., Scheier M. F., & Weintraub, J. K. (1989). Assessing coping strategies: a theoretically based approach. *Journal of Personality and Social Psychology*, 56, 267-283.
- Cidav, Z., Marcus, S. C., & Mandell, D.S. (2012). Implications of childhood autism for parental employment and earnings. *Pediatrics*, 129(4), 617-23.
- Çandır, G. (2015). Investigation of the relationship between depression, anxiety, stress and coping attitudes in the mothers of children aged 4-24 years diagnosed with autism spectrum disorder and down syndrome. Unpublished Master Thesis, Arel University,

- Institute of Social Sciences, İstanbul, 132p (in Turkish).
- Dale, E., Jahoda, A., & Knott, F. (2006). Mothers' attributions following their child's diagnosis of autistic spectrum disorder: exploring links with maternal levels of stress, depression and expectations about their child's future. *Autism*, 10(5), 463-479.
- Darıca, N., Arıboğan, Ü., & Gümüşçü, Ş. (2005). *Autism and autistic children*, Özgür Yayınları. ISBN:9789754471243
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: associations with child characteristics. *Journal* of *Autism* and *Developmental Disorders*, 38(7), 1278-1291.
- Dereli, F., & Okur, S. (2008). Determining the depression status of families with disabled children. *New Medical Journal*, 25, 164-168.
- Dicle, A. N. (2012). The effect of motivational interviewing practices on coping attitudes of families with disabled children. Master Thesis, Ondokuz Mayıs University, Institute of Educational Sciences, Samsun, 197p (in Turkish).
- Durukan, İ., Erdem, M., Tufan, A., & Türkbay, T. (2010). Coping attitudes of mothers of children with autism spectrum disorder and their relationship with depression and anxiety levels, *Journal of Child and Youth Mental Health*, 17(2), 75-82.
- Duygun, T., & Sezgin, N., (2003). The effects of stress symptoms, coping styles and perceived social support on the level of burnout in mothers of mentally retarded and healthy children. *Turkish Journal of Psychology*, 18(52), 53-55.
- Dyches, T. T., Christensen, R., Harper, J., Mandleco, B., & Roper, S., (2016). respite care for single mothers of children with autism spectrum disorders. *Journal of Autism & Developmental Disorders*, 46(3), 812-824.
- Ergin, C. (1992). Burnout in doctors and nurses and adaptation of Maslach Burnout Scale, p.22-25, 7th National psychology congress, 22 September, 1992, Ankara
- Essex, E.L., Seltzer, M.M., & Krauss, M.W. (1999). Differences in coping effectiveness and well-being among aging mothers and fathers of adults with mental retardation. *American Journal of Mental Retardation*, 104(6), 545-563.

- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X. H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, *13*(4), 375-387.
- Eysenck, H. J., & Eysenck, M.W. (1985).

 Personality and Individual Differences: A
 Natural Science Approach. Plenum, New
 York
- Falk, N., Norris, K., & Quinn, M. G. (2014). The factors predicting stres, anxiety anddepression in the parents of children with autism. *Journal of Autism and Developmental Disorders*, 44(12), 3185-3203.
- Firth, I., & Dryer, R. (2013). The predictors of distres in parents of children with autism spectrum disorders. *Journal of Intellectual Development Disabilities*, 38, 163-171.
- Hall, H. R., & Graff, J. C. (2010). Parenting challenges in families of children with autism: A pilot study. *Issues in Comprehensive Pediatric Nursing*, 33(4), 187-204.
- Harris, S. L. (1994). Treatment of family problems in autism. In E. Schopler & G. B. Mesibov (Eds.), *Behavioral Issues in Autism* (1st ed., pp. 161-175). Plenum
- Hastings, R. P., & Brown, T. (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal of Mental Retardation*, 107(3), 222-232
- Hastings, R. P., Kovshoff, H., Ward, N. J., Espinosa, F. D., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, 35(5), 635-644.
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder.

 Journal of Autism and Developmental Disorders, 43(3), 629-642.
- Işıkhan, V. (2005). Problems of mothers with mentally handicapped children in Turkey, Hacettepe University Publications.

- Kaminski, J., Valle, J., Filene, J., & Boyle, C. (2008). A meta-analytic review of components associated with parent training program effectiveness. *Journal of Abnormal Psychology*, 36(4), 567-589.
- Kim, I., Ekas, N. V., & Hock, R. (2016). Associations between child behavior problems, family management, and depressive symptoms for mothers of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 26, 80-90.
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). Theimpact of behavior problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50(3), 172-183.
- Lee, L. C., Harrington, R. A., Louie, B. B., & Newschaffer, C. J. (2008). Children with autism: Quality of life and parental concerns. *Journal of Autism and Developmental Disorders*, 38(6), 1147-1160.
- Lyons, A. M., Leon, S. C., Roecker Phelps, C. A. & Dunleavy, A. M. (2010). The impact of child symptom severity on stress among parents of children with ASD: The moderating role of coping styles. *Journal of Child and Family Studies*, 19, 516-524.
- Machado, S. B. J., Celestino, M. I. O., Serra, J. P. C., Caron, J., & Pondé, M. P. (2016). Risk and protective factors for symptoms of anxiety and depression in parents of children with autism spectrum disorder. *Developmental Neurorehabilition*, 19(3), 146-153.
- Marcus, L. M., Kunce, L. J., & Schopler, E. (1997). Working with families. In D. J. Cohen & F. R. Volkmar (Eds.) *Handbook of autism and pervasive developmental disorders* (1st ed., pp. 631-649). John Wiley & Sons.
- Maslach, C., & Jackson, S. E. (1981). The measurement of experienced burnout. *Journal of Occupational Behavior*, 2, 99-113.
- Mcstay, R. L., Dissanayake, C., Scheeren, A., Koot, H. M., & Begeer, S. (2014). Parenting stress and autism: The role of age, autism severity, quality of life and problem behaviour of children and adolescents with autism. *Autism*, 18(5), 502–510.
- Montes, G., & Halterman, J. S. (2016). Pyschological functioning and coping among

- mothers of children with autism: A population-based study. *Pediatrics*, 119(9), 1040-1046.
- Mulligan, J., MacCulloch, R., Good, B., & Nicholas, D. B. (2012). Transparency, hope, and empowerment: a model for partnering with parents of a child with autism spectrum disorder at diagnosis and beyond. *Social Work* in *Mental Health*, *10*(4), 311-330.
- Nealy, C. E., O'Hare, L., Powers, J. D., & Swick, D. C. (2012). The impact of autism spectrum disorders on the family: A qualitative study of mothers' perspectives. *Journal of Family Social Work*, 15(3), 187-201.
- Norton, P., & Drew, C. (1994). Autism and potential family stressors. The *American Journal of Family Therapy*, 22(1), 67-75.
- Nuri C., Rustioglu O., & Piskin Abidoglu U. (2018). The problems of the families who have autistic children: A qualitative research. *Life Skills Journal of Psychology*, 2(3), 97-111.
- Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment*, 12, 745-762.
- Ou, W. X., Cha, C. H., & Wang, L. H. (2010). Mental health state of parents of children with autism. *Chinese Journal of Contemporary Pediatrics*, 12(12), 947-949.
- Park, E. Y., & Shin, M. (2020). A Meta-Analysis of special education teachers' burnout. *SAGE*, 1-18.
- Poslawsky, I. E., Naber, F. B., Van Daalen, E., & Van Engeland, E. (2013). Parental reaction to early diagnosis of their children's autism spectrum disorder: An exploratory study. *Child Psychiatry & Human Development*, 45(3), 294-305.
- Roxana, U. I., & Carmen, A. (2020). Dimensions of relationships of students with intellectual disabilities. *International Journal of Special Education and Information Technology*, 6(1), 48-60.
- Sariçam, H., & Sakiz, H. (2014). Burnout and teacher self-efficacy among teachers working in special education institutions in Turkey. *Educational Studies*, 40, 423–437.
- Scherer, N., Verhey, I., & Kuper, H. (2019).

 Depression and anxiety in parents of children with intellectual and developmental

- disabilities: A systematic review and metaanalysis. *PLoS One*, *14*(7).
- Seltzer, M. M., Greenberg, J. S., & Krauss, M. W. (1995). A comparison of coping strategies of aging mothers of adults with mental illness or mental retardation. *Psychol Aging*, *10*(1), 64-75.
- Senthilnathan, S. (2017). Relationships and Hypotheses in Social Science Research. *SSRN Electronic Journal*.
- Sivberg, B. (2002). Coping strategies and parental attitudes, a comparison of parents with children with autistic spectrum disorders and parents with non-autistic children. *International Journal of Circumpolar Health*, 61(2), 36-50.
- Stambekova, A., Shmidt, M., T., Galieva, A., Kydyrbaeva, G., Yerzhanova, G., & Issabayeva, Z. (2021). Opinions of disabled university students on the distance education process. World Journal on Educational Technology: Current Issues, 13(4), 1124-1136.
- Şahin, Z, B. (2017). Examination of the relationship between burnout symptoms and coping strategies in mothers of children diagnosed with autism or specific learning difficulties. Unpublished Master Thesis, Haliç University, Institute of Social Sciences, İstanbul, 104p (in Turkish).
- Şengül, S. T., & Baykan, H. T. (2013). Attitudes of coping with depression, anxiety and stress in mothers of mentally retarded children, *Kocatepe Medical Journal*, *14*(1), 30-39.
- Tabachnick, B. G., & Fidell, L. S. (2013). Using Multivariate Statistics (6th edition). Allyn and Bacon.
- Tahincioğlu, C. (2016). The relationship between anxiety levels and burnout in mothers with children with autism. Unpublished Master Thesis, Beykent University, Institute of Social Sciences, İstanbul, 85p (in Turkish).
- Tenerife, J. J. L., Peteros, E., Englatera, J. D., de Vera, J. V., Pinili, L. C., & Fulgencio, M. D. (2022). Exploring predictors of adaptive behaviour of children with autism. *Cypriot Journal of Educational Sciences*, 17(3), 772-786.
- Uğuz, Ş., Toros, F., İnanç, B.Y., & Çolakkadıoğlu, O. (2004). Determination of anxiety, depression and stress levels of mothers of

- mentally and/or physically handicapped children. *Clinical Psychiatry*, 7, 42-47.
- Ulusoy, M., Şahin, N. H., & Erkmen, H. (1998). Turkish version of the Beck Anxiety Inventory: Psychometric properties. *Journal* of *Cognitive Psychotherapy*, *12*, 163-172.
- Üstüner Top, F. (2009). Evaluation of the problems and mental states of families with autistic children: Qualitative research. *Journal of Child*, *9*(1), 34-42.
- Varol, N. (2005). Family Education. Kök Yayıncılık. ISBN: 9789754993011.
- Vohra, R., Madhavan, S., Sambamoorthi, U., & St Peter, C. (2014). Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism*, 18(7), 815-26.
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: the experience of parents who have a child with autism. *Qualitative Health Research*, 18(8), 1075-1083.

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