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Examination of Care Burden and Stress Coping Styles of Parents of Children with Autism Spectrum Disorder

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ABSTRACT

Objective: The study was conducted to examine the caregiver burden and stress coping styles of parents of children with Autism Spectrum Disorder (ASD).
Design and methods: This descriptive cross-sectional study was conducted with parents of 131 children with ASD who were enrolled in a private education practice center in Istanbul between August 2015 and August 2016. The data were collected using a questionnaire prepared by the researchers, and the "Caregiver Strain Index" and "Ways of Coping Questionnaire."
Results: The mean age of the children in the sample group was 4.83 ± 0.99 years; 63.4% were boys. Nearly 40% (38.2%) were diagnosed as having ASD at the age of 2 years. It was determined that the parents of children with ASD had a higher burden of care (CSI mean score: 7.68 ± 4.30). The caregiver burden was significantly higher ($p < 0.05$) for parents of one child as compared to parents with more children, and parents with daughters compared to parents with sons. In addition, the mothers were found to have higher scores of 'submissive approach' and 'seeking social support' than fathers.
Conclusion: Parents of children with ASD had a higher caregiver burden. Scores of approach types of self-confident, helpless, optimistic, and seeking social support were significant predictors of caregiver burden.
Practice implications: Nurses are encouraged to take a more active role to improve the health of children with autism and families should contribute to mitigating the burden care of parents by informing families about social support systems.

Introduction

Autism Spectrum Disorder (ASD) is characterized by persistent deficits in social communication, reciprocity, and interaction; and a lack of skills in developing, maintaining, and understanding relationships. In addition, the diagnosis of ASD requires the presence of restricted, repetitive patterns of behavior, interests, or activities. It has been reported that one in every 68 children is affected by ASD (Baird et al., 2006; CDC, 2014; Durmaz, 2017; Fombonne, 2009).

Parents are an important part of the family environment, playing a central role in the developmental outcome of children (Altiere & Kluge, 2009). Parents of children with autism take on excessive responsibilities such as meeting social, physical, emotional, and learning needs of a child, and this situation causes stress, despair, and anxiety (Duarte, Bordin, Yazigi, & Mooney, 2005; Durukan, Erdem, Türkbey, & Cöngöloğlu, 2009; Metin, 2012; Pisula, 2007). It has been clearly demonstrated in the existing literature that the parents of children with autism report more mental health problems than the parents of children with other diseases (Falk, Norris, & Quinn, 2014; Giovagnoli et al., 2015).

Bringing up a child with autism can be a stressful experience for parents (Seymour, Wood, Giallo, & Jellett, 2013; Zablotsky, Bradshaw, & Stuart, 2013). Studies that compared the stress in families with a child with autism to families of children with other disorders indicated that the families of children with autism experienced more stress, depression, and anxiety (Altiere & Kluge, 2009; Pisula, 2007; Seymour et al., 2013; Zablotsky et al., 2013). It has been shown that parents of children with ASD have high levels of stress, frequent physical and mental burnout, and poor coping skills (Benson, 2010; Dale, Jahoda, & Knott, 2006; Durmaz, 2017; Hastings, Kovshoff, Brown, et al., 2005; Yurdakul, Girli, Ozekes, & Sarısoy, 2000).

The increased stress level puts parents at particular risk for emotional and psychological distress (Zablotsky et al., 2013). Some research in recent years has focused on the difficulties that parents face related to caring for a child with autism, and the strategies employed to cope with

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the stress associated with raising these children (Altiere & Kluge, 2009; Benson, 2010; Hastings, Kovshoff, Brown, et al., 2005; Patterson, 2002).

Coping strategies have been posited as one mechanism by which individuals respond to threats of stress, including stressors associated with parenting of a child with autism. Researchers have often grouped coping methods into two general types, problem-based coping (strategies aimed at solving the problem or doing something to change the source of stress) and emotion-based coping (strategies aimed at reducing or managing feelings of distress associated with the stressor) (Benson, 2010; Hastings, Kovshoff, Brown, et al. (2005), Patterson, 2002). Studies of parents with a child with autism have examined this interaction by focusing on the effect parents have on the child, not the child's effect on the parents (Altiere & Kluge, 2009).

In studies of parents of individuals with autism, use of emotion-focused coping strategies (e.g., denial) have generally been found to be associated with higher levels of psychological distress, while use of problem-focused coping methods (e.g., planning, taking action to address the problem) have often been associated with improved mental health outcomes (Benson, 2010).

It is known that, the stress of parents of children with autism affects the burden of care (Benson, 2010; Hastings, Kovshoff, Ward, et al., 2005; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). The presence of coping supports has the potential to reduce a parent's risk for developing depression and other forms of psychopathology (Zablotsky et al., 2013). Hastings, Kovshoff, Ward, et al. (2005) found passive avoidant and religious/denial coping to be significantly related to increased parent stress, anxiety, and depression, while problem-focused coping was unrelated to any of these distress measures. The existing literature on coping by parents of children with autism is limited and leaves many key issues unresolved (Benson, 2010). Some studies of families of children with autism have examined how different coping methods are associated with parent distress and well-being, and, in particular, whether the effects of different coping strategies on parent outcomes are moderated by child characteristics (Benson, 2010). Seymour, Wood, Giallo Jellett, (2013) suggested that child behavior difficulties might contribute to parental fatigue, which in turn might influence the use of ineffective coping strategies and increased stress. However, factors associated with stress, which affect the coping strategies used by parents, have not been examined sufficiently (Benson, 2010; Smith et al., 2008).

The aim of the present study was to contribute to the literature on autism and examine the caregiver burden and stress coping styles of parents of children with autism. This study examined the following hypotheses: (Abrahams & Geschwind, 2008) Parents of children with autism will have a higher stress and caregiver burden; (Altiere & Kluge, 2009) Mothers of children with autism will exhibit more coping mechanisms than fathers; (Baird et al., 2006) Mothers of children with autism will perceive having more social support than fathers.

Method

Study period and sample

This study was conducted between January and December 2017 at a special education center located in Istanbul that provides services to children with ASD. It was aimed that all parents who had children with ASD would agree to participate in the study (N = 143), without using sample selection. Twelve parents were excluded because they declined to participate in the study. The study sample consisted of 131.

Study setting

Seven education coordinators including the institution manager, a special education specialist, child development specialist, psychological counselor, psychiatric services specialist, physiotherapist, social service specialist, and 13 house educators work in the education center where the data were collected. The center provides education and consulting services to children and families in their homes in accordance with the education program of the institution. In addition, the families and their children come to the center one day per week in order to receive special education and counseling services.

Data collection

A data collection form was prepared by the researchers after a literature review of Benson (2010), Hastings, Kovshoff, Brown, et al. (2005), Sencar (2007), Şahin (2017), Trabzon (2016), and the "Caregiver Strain Index", and "The Coping Patterns Scale" were used to collect data.

The Data Collection Form consisted of the questions including sociodemographic characteristics regarding the parents and the children, information on the disease, and the effect of the disease on the parents. In order to test the comprehensibility of the data collection forms, a pilot study was conducted with 10 mothers.

The Caregiver Strain Index-CSI was developed by Robinson in 1983, to measure caregiver burden. The Turkish validity and reliability study of the scale was conducted by Uğur (2006). The scale is composed of 13 items (yes: 1, no: 0) related to business, economic, physical, social, and time parameters. The lowest score that can be obtained from the scale is 0, the highest is 13. A score of 7 or above indicates that the parent's stress and caregiver burden are high. The Cronbach's alpha coefficient of the CSI in patients in the sample group was 0.90.

The Ways of Coping Questionnaire-WCQ was developed by Folkman and Lazarus in 1980, to determine the approaches used by individuals for coping. The scale was adapted to Turkish participants by Şahin and Durak (1995). The scale, which is composed of 30 items, is rated using a 4-point Likert-type scale (0: not suitable at all, to 3: very suitable). The scale is comprised of 5 subscales: The Self-Confident Approach, the Optimistic Approach, the Helpless Approach, the Submissive Approach, and Seeking Social Support. The Cronbach's alpha coefficient of the WCQ was 0.64 in the patients in the sample group.

The parents were asked to complete the forms and tools on a day when they brought their children to the education center. It took approximately 20 min to complete the forms and tools.

Ethical approval

Before starting data collection, ethics committee approval was received from Okan University Ethics Committee and written permission was received from the institution where the study was conducted. The parents were informed about the purpose of the study before the study, by considering the voluntariness principle in the participation in the study and their verbal consents were obtained.

Data analysis

The data were analyzed using the SPSS 21.0 program. Categorical variables are expressed as percentages, and continuous variables are expressed as means, standard deviations, and medians. Correlations between factors that affected stress levels and the coping styles of the parents were examined using the independent samples *t*-test and one-way ANOVA. Factors that affected stress levels and the coping styles of the parents were analyzed using simple linear regression. The level of statistical significance was determined as $p < 0.05$.

Results

The average age of the children in the sample group was 4.83 ± 0.99 years. The majority (63.4%) were boys, and (61.1%) had siblings. Some (38.2%) of the children were diagnosed at the age of two years and 19.8% had comorbidities. The interviewed parents were mostly mothers (72.5%), 55.7% were aged 36 years and over, 61.8% were unemployed, and 61.8% had primary school education only. The income of more than half of the parents (52.7%) was equal to the expenses, and

14.5% of them had kinship relationships (consanguineous marriage) (Table 1). Three-quarters (75.6%) of the parents stated that their daily lives were affected and the relationships of 18.3% of the parents with their spouses were affected due to the disease condition of the children.

The 'self-confident approach' and the 'optimistic approach' scores of parents of 3-year-olds were found to be lower than those of other ages ($p < 0.05$). The CSI scores of the parents of girls were significantly higher statistically compared with the parents of boys ($p < 0.05$). The CSI scores of the parents of children who have no siblings were significantly higher statistically compared with the parents of children with siblings ($p < 0.05$). The 'submissive approach' and the 'seeking social support' scores of the mothers were significantly higher as compared with the fathers, and the 'self-confident approach' subscale scores of the fathers were statistically significantly higher than the mothers' ($p < 0.05$). The 'self-confident approach' scores of employed parents, and the 'submissive approach' and 'seeking social support' scores of unemployed parents were significantly higher ($p < 0.05$). The CSI scores of parents who had kinship with their spouses were significantly lower compared with parents who had no kinship with their spouses ($p < 0.05$). The WCQ helpless approach subscale score and CSI mean score of the parents whose activities of daily living were affected due to the condition of children with ASD were significantly higher statistically ($p < 0.05$) (Table 2).

It was found that the parents' stress and caregiver burden were high (CSI mean score: 7.68 ± 4.30). When the caregiver burden (CSI score) was included in the equation as explanatory, it was observed in the model formed with the WCQ subscales that the self-confident approach (30.5%) and the optimistic approach (21.4%) were explained in the negative direction and the helpless approach (30.9%) and the seeking social support (17.4%) were explained in the positive direction, and there was a significant statistical correlation ($p < 0.05$) (Table 3).

Table 1
The descriptive characteristics of the children and the parent (n = 131).

	n	%
Age (mean) (4.83 ± 0.99) years		
3 years	17	13.0
4 years	26	19.8
5 years	49	37.4
6 years	39	29.8
Sex		
Girl	48	36.6
Boy	83	63.4
The child's age at diagnosis		
First year of the life	21	16.0
2 years	50	38.2
3 years	43	32.8
4 years and over	17	13.0
Presence of comorbidities of the child		
Yes	26	19.8
No	105	80.2
The interviewed parent		
Mother	95	72.5
Father	36	27.5
Age of parent		
23–35 years	58	44.3
36 years and over	73	55.7
Employment status		
Employed	50	38.2
Unemployed	81	61.8
Educational status		
Primary school graduate	81	61.8
High school graduate	27	20.6
University graduate	23	17.6
Income status		
The income is less than expenses	62	47.3
The income is equal to the expenses	69	52.7
Consanguineous marriage		
Yes	19	14.5
No	112	85.5

Discussion

The aim of the study was to examine the caregiver burden and stress coping styles of parents of children with ASD and the associated factors. It was determined that the caregiver burden of parents with children with ASD in the sample group was high. Parents who make effective use of strategies for coping with stress adapt themselves more easily, and individuals who use positive strategies for coping with stress develop solution-oriented positive behaviors (Patterson, 2002; Trabzon, 2016). Hastings, Kovshoff, Brown, et al. (2005) reported four key coping dimensions relevant to raising a child with autism-avoidance coping, problem focused coping, positive coping, and religious coping.

Hastings, Kovshoff, Brown, et al. (2005) suggested that the use of positive reframing of potentially traumatic and stressful events might be one of the only effective coping strategies available to families under extreme conditions. In the caregiver burden of parents in the sample group, the self-confident approach and optimistic approach among the methods of coping with stress were negative significant predictors, and the helpless approach and seeking social support were positive significant predictors. It is stated that social support is compatible with problem-focused and emotion-focused categories (Benson, 2010). Hastings, Kovshoff, Ward, et al. (2005) determined that the well-being levels of parents of children with autism who used problem-focused coping were higher compared with parents using emotion-focused coping; and that families with children with disabilities mostly used problem-solving and support seeking, and avoidance was the least used coping strategy (Glidden, Billings, & Jobe, 2006; Yurdakul et al., 2000).

Smith et al. (2008) suggested that the use of problem-focused coping strategies had a minimal effect on reducing maternal distress; however, using avoidance strategies increased parent distress. Benson (2010) investigated the coping methods used by mothers of children with autism and reported that the coping methods were associated with the well-being levels of the mothers. Altiere and Kluge (2009) determined no significant differences in a comparison of family functions and coping mechanisms; however, there were differences between the coping strategies of the parents. Although the families benefited from social support, this subject requires further research in different groups in terms of examining caregiver burden and coping strategies.

It was observed that the caregiver burden of the parents of girls was higher than in the parents of boys. There are conflicting findings in studies that examined the effect of the sex of children with autism on the stress and mood of the parents. Durmaz (2017) reported that the hopelessness levels of mothers with a daughter with ASD were significantly higher compared with parents of boys with ASD. Görgü (2005) and Sencar (2007) concluded that the sex of the child had no effect on the stress of the parent. Parents have lifelong anxiety and stress because they think that children with ASD should be protected and supported throughout life. The fact that the caregiver burden of parents of girls was higher in our study may be explained by the fact that there is a culturally more protective approach for girls in Turkey.

It was observed that the parents whose children were at the age of 4,5, and 6 used the self-confident approach and optimistic approach more than the parents whose children were at the age of three. Yurdakul et al. (2000) reported that the age of the child was an important factor that affected stress levels, and Duarte et al. (2005) reported that the stress levels of mothers with younger children with autism were higher. Durmaz (2017) also found that the anxiety of mothers decreased as the age of the child with autism increased. Trabzon (2016) determined that as time elapsed after the diagnosis of the child, the optimistic approach and self-confident approach scores of the parents increased. Increased self-confident approach, and optimistic approach scores with increasing age of the child may be explained by the fact that the parents accepted the condition over time. Also, it is possible that the family became more accustomed to it, learned more about it, began to see some improvements after therapies, or were able to

Table 2
The comparison of scores of caregiver strain index and subscale scores of ways of coping questionnaire in terms of the descriptive characteristics of the children and the parent (n = 131).

Variables	Self-confident approach	Optimistic approach	Helpless approach	Submissive approach	Seeking social support	CSI
Age	Mean ± sd	Mean ± sd	Mean ± sd	Mean ± sd	Mean ± sd	Mean ± sd
3 years	1.77 ± 0.45	1.62 ± 0.55	1.44 ± 0.36	1.11 ± 0.54	2.01 ± 0.54	8.24 ± 4.02
4 years	2.41 ± 0.39	2.00 ± 0.44	1.20 ± 0.61	0.98 ± 0.68	2.00 ± 0.52	6.92 ± 4.73
5 years	2.04 ± 0.45	1.96 ± 0.35	1.36 ± 0.51	1.36 ± 0.46	1.79 ± 0.64	7.78 ± 4.34
6 years	2.01 ± 0.46	1.95 ± 0.34	1.31 ± 0.56	1.32 ± 0.62	2.03 ± 0.45	7.82 ± 4.16
F	7.702	3.758	0.803	3.043	1.631	0.379
p	0.000[*] (4 > 3; 5 > 3; 6 > 3)	0.013[*] (4 > 3; 5 > 3; 6 > 3)	0.494	0.031[*] (5 > 4)	0.185	0.768
Sex						
Girl	2.01 ± 0.501	1.93 ± 0.415	1.34 ± 0.468	1.23 ± 0.598	1.93 ± 0.589	8.73 ± 3.874
Boy	2.09 ± 0.469	1.92 ± 0.415	1.32 ± 0.572	1.25 ± 0.581	1.94 ± 0.551	7.07 ± 4.439
t	−0.973	0.028	0.225	−0.172	−0.043	2.154
p	0.332	0.978	0.823	0.863	0.965	***0.033***[*]
Having a sibling						
Yes	2.06 ± 0.48	1.93 ± 0.45	1.34 ± 0.61	1.23 ± 0.59	1.23 ± 0.59	6.73 ± 4.33
No	2.08 ± 0.05	1.91 ± 0.35	1.31 ± 0.40	1.21 ± 0.16	1.26 ± 0.57	9.18 ± 3.83
t	0.184	−0.219	−0.231	0.267	1.132	3.300
p	0.854	0.827	0.818	0.790	0.260	***0.001***[*]
The interviewed parent						
Mother	1.96 ± 0.43	1.90 ± 0.41	1.35 ± 0.52	1.36 ± 0.56	2.02 ± 0.56	7.71 ± 4.55
Father	2.33 ± 0.50	1.96 ± 0.42	1.26 ± 0.56	0.93 ± 0.54	1.70 ± 0.52	7.61 ± 0.61
t	−4.101	−0.636	0.834	4.051	3.010	0.111
p	***0.000***[*]	0.526	0.406	***0.000***[*]	***0.003***[*]	0.911
Age of parent						
23–35 years	2.00 ± 0.51	1.86 ± 0.45	1.32 ± 0.48	1.27 ± 0.60	1.85 ± 0.60	7.57 ± 4.14
36 years and over	2.12 ± 0.44	1.96 ± 0.37	1.32 ± 0.57	1.22 ± 0.57	2.00 ± 0.52	7.77 ± 4.44
t	−1.462	−1.352	−0.035	0.449	−1.485	−0.261
p	0.146	0.179	0.972	0.654	0.140	0.795
Employment status						
Employed	2.24 ± 0.53	1.94 ± 0.51	1.30 ± 0.58	1.09 ± 0.64	1.68 ± 0.51	7.60 ± 3.75
Unemployed	1.96 ± 0.41	1.91 ± 0.33	1.33 ± 0.50	1.33 ± 0.52	2.08 ± 0.53	7.73 ± 4.62
t	3.320	0.440	−0.332	−2.358	−4.242	−0.165
p	***0.001***[*]	0.660	0.741	***0.020***[*]	***0.000***[*]	0.869
Educational status						
Primary education	2.09 ± 0.49	1.92 ± 0.42	1.36 ± 0.55	1.27 ± 0.59	1.93 ± 0.52	7.51 ± 4.63
High school	1.96 ± 0.38	1.86 ± 0.40	1.25 ± 0.55	1.26 ± 0.53	1.99 ± 0.69	8.44 ± 3.83
University	2.08 ± 0.53	1.99 ± 0.40	1.26 ± 0.45	1.12 ± 0.63	1.85 ± 0.53	7.39 ± 3.57
F	0.750	0.559	0.591	0.594	0.340	0.541
p	0.475	0.573	0.555	0.554	0.712	0.584
Consanguineous marriage						
Yes	2.14 ± 0.67	1.93 ± 0.48	1.18 ± 0.62	1.08 ± 0.50	1.78 ± 0.58	5.11 ± 3.95
No	2.05 ± 0.44	1.92 ± 0.40	1.35 ± 0.51	1.27 ± 0.59	1.95 ± 0.55	8.12 ± 4.21
t	0.725	0.150	−1.264	−1.263	−1.220	−2.901
p	0.470	0.881	0.208	0.209	0.225	***0.004***[*]
Status of ADL[a] of the parent to be affected						
Affected	2.04 ± 0.47	1.89 ± 0.41	1.39 ± 0.49	1.26 ± 0.58	1.94 ± 0.59	8.75 ± 3.79
Not affected	2.14 ± 0.51	2.01 ± 0.41	1.11 ± 0.60	1.17 ± 0.58	1.89 ± 0.47	4.38 ± 4.14
t	−1.063	−1.402	2.665	0.803	0.422	5.542
p	0.290	0.163	***0.009***[*]	0.423	0.674	***0.000***[*]
Status of the relationship between the spouses						
Affected	2.00 ± 0.48	1.77 ± 0.49	1.19 ± 0.62	1.13 ± 0.62	1.87 ± 0.51	7.25 ± 3.68
Not affected	2.08 ± 0.48	1.95 ± 0.38	1.35 ± 0.51	1.26 ± 0.57	1.94 ± 0.57	7.78 ± 4.43
t	−0.705	−1.968	−1.315	−0.975	−0.576	−0.540
p	0.482	***0.051***[*]	0.191	0.331	0.565	0.590

t = Independent samples *t*-test; F = One-wayANOVA, Tukey test.

[*] $p < 0.05$.

[a] ADL: Activities of Daily Living.

Table 3
The prediction of the parents' subscale scores of caregiver strain index and ways of coping questionnaire (n = 131).

Dependent: CSI (mean score: 7.68 ± 4.301)	B	Standard error	Beta (R^2)	t	p
Self-confident approach	−0.389	0.107	−0.305	−3.631	<0.001[a]
Optimistic approach	−0.445	0.179	−0.214	−2.492	0.014[a]
Helpless approach	0.310	0.084	0.309	3.684	<0.001[a]
Submissive approach	0.147	0.107	0.120	1.378	0.171
Seeking social support	0.331	0.165	0.174	2.004	0.047[a]

$R^2 = 0.47$.

[a] CSI: The Caregiver Strain Index (CSI).

identify some sources of support. It may be thought that parents who accept the condition of their child would be more optimistic and their self-confidence would increase.

The submissive approach and seeking social support scores of the mothers were higher compared with the fathers, and the self-confident approach scores of the fathers were higher than those of mothers. When examining studies conducted with parents of children with autism, it has been reported that mothers are mentally affected more than fathers (Hastings, Kovshoff, Ward, et al., 2005; Sunay, 2000). Glidden et al. (2006) found that mothers used problem-focused coping more than fathers. Elçi (2004) investigated the effect of social support, stress levels, and coping ways in families of children with autism on posttraumatic growth and burnout and reported that mothers experienced more burnout than fathers. Altiere and Kluge (2009) compared the coping mechanisms of parents of children with autism and determined that the mothers received more social support from their friends and families. Bilgin and Küçük (2010) suggested that the mothers needed social support in order to cope with stress, pointing out that the mothers with high social support perception reported less somatic problems and depressive symptoms (Altiere & Kluge, 2009). It has been reported that depression and anxiety are the most powerful predictors in mothers with low social support levels (Boyd, 2002). The results of the present study support the results of Altiere and Kluge (2009) and Bilgin and Küçük (2010), indicating that the mothers seek social support more. Koydemir and Tosun (2009) stated that mothers of children with autism had difficulties and experienced burnout because they took care of their children on their own. It may be asserted that the mothers' submissive approach and seeking social support scores were higher compared with the fathers because they shoulder more of the caregiver burden of their children.

The self-confident approach used in coping with stress had a negative association with the employment of the parents. It is found that, the parents who are employed, use the self-confident approach more than the parents who are unemployed. Also, it is seen that the parents who are unemployed, use the submissive approach and seek social support more than the parents who are employed. In a similar study, Şahin (2017) reported that the employment of mothers who had children with autism had no effect on their coping strategies. The existing literature on coping by parents of children with autism is limited and leaves many issues unresolved.

Limitation

The results of the study cannot be generalized because they were received from a single special education center.

Clinical implications

Parents have lifelong anxiety and stress because they believe that their children with ASD should be protected and supported throughout life. Family centered care guides nursing practice; assessment of the parents' coping styles and burden of care is relevant to addressing the comprehensive needs of parents with children with autism. Once it has been identified that families, in particular mothers, experience significant distress, it is important for nurses working with these families to use strategies to help alleviate some of the distress. Nurses working with children with autism need to assess the coping style of their parents understanding the negative emotions of the parents can experience, such as stress, anxiety, and implement interventions to support them. These interventions will vary depending on their coping styles. Nurses are encouraged to take a more active role to improving the health of children with autism and families and contribute to mitigating the burden care of parents by informing them about social support systems. There are many nursing care options nurses could undertake with the information presented here, serve as advocates for families, educate them about autism, connect them to sources of support.

Treatment for children with ASD, as well as social support services for these children and their families, are not adequate in Turkey. The care of children with autism is entirely the responsibility of the families. Many families have been abandoned to their fate. Parents can be directed to forums and autism-related associations in Turkey where they can communicate each other and share their experiences. These social networks could help parents strengthen social support systems by facilitating communication with families of similar characteristics.

Conclusion

Parents of children with ASD have significant psychological distress, high levels of stress, frequent physical and mental burnout, and insufficient coping skills. In terms of factors that affect the coping of parents, caregiver burden, and coping strategies, the subject should be investigated further in different groups. It may be suggested that the stratification of the coping strategies of the parents of children with autism be determined by assessment tools and that solutions for parents should be developed to reduce the burden of care.

CRediT authorship contribution statement

Gülçin Bozkurt: Project administration, Methodology, Validation, Writing - original draft. **Gülzade Uysal:** Methodology, Resources, Software, Validation, Writing - review & editing. **Duygu Sönmez Düzkaya:** Methodology, Resources, Validation.

CRediT authorship contribution statement

Gülçin Bozkurt: Project administration, Methodology, Validation, Writing - original draft. **Gülzade Uysal:** Methodology, Resources, Software, Validation, Writing - review & editing. **Duygu Sönmez Düzkaya:** Methodology, Resources, Validation.

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