# Research article



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#### **ABSTRACT**

Having a child with autism may have a strong impact on the family, especially on mothers, who are usually the primary caregivers of children with autism. Parents of children with autism report more mental health problems compared to parents of children with normal development or other developmental disabilities. Parental copying strategies may play a significant role when parents have to overcome stressful situations during the child's development. The present study aimed to investigate the coping strategies used by mothers of children with autism spectrum disorder (ASD) and their relation to maternal stress and depression. One hundred and forty-three (143) mothers (mean age 42.7 years) of children with ASD (6-17 years), who attended the ASD Outpatient Clinic of the Department of Child Psychiatry, at a Children's Hospital, participated in the current study. Mothers completed a series of questionnaires: a demographic characteristics questionnaire, the Center for Epidemiologic Studies Depression Scale (CES-D), the Family Crisis Oriented Personal Scales (F-COPES) and the Parenting Stress Index Short-Form (PSI-SF). Mothers with higher educational level scored significantly lower in total F-COPES and its subscale "reframing". Increased daily hours related to child care and the child's medication schedule were additional factors significantly associated with lower scores on "reframing". Reframing subscale was also negatively correlated with "parental distress", whereas "passive appraisal" was positively correlated with depressive symptoms. Lower scores on "mobilizing family to acquire" and "accept help" were associated with family life being more seriously affected. Coping strategies of mothers of children with ASD are associated with a number of factors related to personal characteristics of caregivers, child treatment and family characteristics. Mental health professionals should examine factors that may strengthen coping strategies that handle the challenges of having a child with ASD.

**KEYWORDS:** Autism spectrum disorders, coping strategies, depression, parental stress.

#### Introduction

Autism Spectrum Disorder (ASD) refers to a range of complex developmental and neurological disorders that include deficits in social communication, as well as stereotyped, restricted and repetitive behaviors and interests.<sup>1</sup> Individuals with autism do not constitute a homogenous population but they vary in terms of onset, symptoms, and severity.<sup>2</sup>

Having a child with autism has an impact on the family.<sup>3–8</sup> Upon receiving the diagnosis of their child's

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disorder, it is possible for the parents to experience frustration due to their expectations for a normally developing child.<sup>9,10</sup> In the existing literature it has been clearly demonstrated that parents of children with autism report more mental health problems than parents of children with normal development or other developmental disabilities.<sup>11</sup> As Sharpley et al noted,<sup>12</sup> the three more powerful stressors arising from raising a child with ASD were (1) the permanent nature of the disorder, (2) the dearth of acceptance of autistic behavior by family members and society and (3) the lack of sufficient support supplied by health care services and other social services. Also, it became clear that autism affected the family organization in dramatic ways. Parents describe feelings of loss and desperationfollowing their child's diagnosis; however, they are willing to activate every possible resource to assist their child.13

Parents vary considerably in their ability to adequately meet the challenges posed by their child's autism, with some of them experiencing little difficulty and others developing serious mental health problems. A qualitative study, identified nine positive themes and 15 negative themes, that were subsumed into five clusters: (1) child's behavior, (2) social isolation, (3) impact on the whole family, (4) stress and (5) parents' personal well-being, work and marital relationship. According to the researchers, the mix of both positive and negative themes could be interpreted as a dialectical standpoint of finding positive meaning to life, although having a child with autism was acknowledged as a source of stress and obstacles. 16

It should not be overlooked that high levels of stress, when left unmanaged, can lead to the development of depressive symptoms, 17-21 a finding that further underscores the importance of coping supports. In addition to the aforementioned finding, it has been shown that the risk for poor mental health and high stress levels can be reduced by the presence of strong maternal coping skills and coping strategies, in the form of emotional and neighborhood social supports.<sup>21</sup> Especially mothers of an autistic child, as the primary caregivers, have higher stress levels and are more likely to report mental health problems, compared to mothers in the general population.<sup>22–24</sup> In particular, a study showed that mothers of children with ASD reported higher levels of negative affectivity, anxiety, parental stress and social inhibition, as well as higher levels of avoidance coping, compared to those of normally developing children.<sup>21</sup> Another study also found increased levels of parental anxiety and depression and impaired quality of life, mainly in mental health and social functioning. This psychosocial burden was related to female gender, increased number of children and higher child's age.<sup>23-25</sup>

A review of coping strategies of parents of children with ASD<sup>26</sup> indicated that parental strategies were influenced by (1) demographic characteristics, (2) psychological attributes (e.g., personality, coping styles, emotional health etc.), (3) child characteristics and (4) situational variables (e.g., family function, treatment availability etc.). Parents of children with ASD use several coping strategies that include: (1) seeking treatment or intervention and information, (2) seeking social support, (3) reappraisal and reframing, (4) adjusting to child's needs, (5) spirituality and (6) seeking respite. Based on the findings of their review, the authors stressed that parents of children with ASD used both problem-focused (e.g., treatments/interventions for child, reappraisal, and reframing) and emotion-focused (e.g., social support, spirituality, and respite) coping strategies. Additionally, a recent study with parents of children with ASD, mainly mothers, found that social support was reported as one of the most beneficial coping strategies.<sup>27</sup>

In light of the above mentioned studies, the present work examines the coping strategies used by mothers of children with ASD in relation to maternal stress and depressive symptoms. The associations between child characteristics, demographic factors and mothers' coping strategies are also explored.

Hence, our research hypotheses were as follows: (1) maternal coping strategies will be related to child age, daily hours for child care and treatment, (2) family demographic characteristics will be related to maternal coping strategies and (3) maternal coping strategies will be related to maternal distress and depression.

## **Material and Method**

## **Participants**

One hundred forty-three (143) mothers (mean age: 42.7, SD: 7.0 years; husbands mean age=47.2, SD=6.4years) with a child (6–17years, mean age: 10.0, SD=3.0 years, 79% boys) with ASD, who attended the ASD Outpatient Clinic of University Department of Child Psychiatry, in "Aghia Sophia" Children's Hospital participated in the study. The majority of the participants were married (70.0%) and 55.2% of them had high educational level (University/or post-graduate studies). The participation criterion was the ability to speak and write fluently in Greek.

# Procedure

The researcher initially informed parents who were coming for a prearranged follow-up appointment to the ASD Outpatient Clinic about the study and scheduled home visits. During the home visits the participants signed the consent forms and completed the questionnaires. Ethical approval of the study was obtained by

the scientific committee of the "Aghia Sophia" Children's Hospital, Athens, Greece.

#### Measures

# Child Diagnosis and Clinical Characteristics

All children had been diagnosed with ASD based on ICD-10 criteria for Pervasive Developmental Disorders. They all underwent a standard psychometric evaluation and were tested for fragile X and other chromosomal abnormalities.

# Demographic Characteristics Questionnaire

This questionnaire, which was developed for the purpose of the current study, includes questions about the child's gender and age, the parents' age, nationality, marital status, educational/ occupational status, the number of children in the family and social support (e.g., partner, family, friends and therapeutic specialists).

# Center for Epidemiologic Studies Depression Scale<sup>28</sup>

It is a self-reported questionnaire that consists of 20 items, measuring the presence of depressive symptoms in the past week, on a 4-point scale ranging from 0 (rarely) to 3 (most of the time). It has good psychometric properties<sup>29</sup> (Cronbach alpha for the present study was 0.74).

# Family Crisis Oriented Personal Scales (F-COPES)30

It consists of 30 coping behavior items, evaluating the family's coping style. It includes two types of interaction: (a) the way a family internally handles difficult situations and problems and (b) the way that the family interacts with the social environment, when asking for help in order to find solutions. The responses ranging from 1 (strongly agree) to 5 (strongly disagree) explore internal and external family-coping patterns It includes five subscales: (a) acquiring social support, (b) reframing, (c) seeking spiritual support, (d) mobilizing family to acquire and accept help and (e) passive appraisal. The total score shows the degree to which the family uses a specific coping strategy. It is a reliable and valid tool, that measures coping strategies and level of adaptation. The Greek version has satisfactory psychometric properties<sup>31</sup> (Cronbach alpha for this study was 0.83).

# Parenting Stress Index Short-Form (PSI-SF)32

It consists of 36 items and comprises three subscales, namely the Parental Distress (PD), Parent-Child Dysfunctional Interaction (PCDI) and Difficult Child (DC) subscales. The PD subscale measures anxiety due to personal factors related to parenting; the PCDI subscale assesses how parents perceive their interactions with

their children and the DC subscale measures the characteristics of child behavior and how difficult it can be to deal with such behavior. Child and Parent domains combine to form the total parental stress. Participants answer according to a 5-point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree).<sup>33</sup> Reliability and validity of the test supports that parenting stress is a useful measure across diverse populations.<sup>34</sup> Studies with Greek population have shown high internal consistency.<sup>35</sup> In our study Cronbach alpha was 0.82, 0.86 and 0.88 for the PCDI, PD and DC, respectively.

# Statistical analysis

Pearson correlations coefficients were used to explore the association of F-COPES with PSI dimensions and CES-D. Also, partial correlation coefficients were computed to explore the association of F-COPES with PSI dimensions and CES-D controlling for child and parent characteristics. The normality assumption was evaluated using the Kolmogorov-Smirnov criterion. Multiple linear regression analyses were conducted in order to find independently associated factors with F-COPES dimensions. The regression equation included terms of child and parent demographic and clinical characteristics. Adjusted regression coefficients (B) with standard errors (SE), were computed from the results of the linear regression analyses. Also, coefficients of determination (R2) of the regression models were reported. All reported p values are two-tailed. Statistical significance was set at p<0.05 and analyses were conducted using SPSS statistical software (version 22.0).

## **Results**

Demographic and family characteristics of the sample are displayed in table 1. The mean age of the mothers was 42.7 years (SD=7.0 years) and the mean age of the husbands was 47.2 years (SD=6.4 years). Concerning children, 79% were boys and 21% girls and their mean age was 10.0 years (SD=3.0 years). The majority of the participants were married (70.0%) and 55.2% of them had high educational level (University/or post-graduate studies). The majority of mothers (71.3%) declared that the presence of the child with autism affects family's social life and 34.3% reported more than five hours of daily care of the child. The mean number of stressful events reported for the last year was 1.8 (SD=1.6). 49% of the children were under pharmacological treatment and more than half of the mothers (58%) reported having a health problem.

Results from multiple linear regression analyses with dependent variables Reframing, Mobilizing Family to acquire and Accept Help and Seeking Spiritual Support are shown in tables 2 and 3. Concerning Reframing, it was

Table 1. Sample characteristics.

	N (%)
Mothers with a child with ASD	143 (100)
Child's gender	
Boys	113 (79.0)
Girls	30 (21.0)
Child's age (years), mean (SD)	10.0 (3.0)
Mother's age (years), mean (SD)	42.7 (7.0)
Father's age (years), mean (SD)	47.2 (6.4)
Educational status of them others	
Primary/Middle/High school or 2-year college	64 (44.8)
University/ Post-graduate studies	79 (55.2)
Married	100 (70.0)
Number of children in the family	
1	36 (25.2)
2	84 (58.7)
>2	23 (16.1)
The presence of the child affects family's social	life
Not at all	41 (28.7)
A little	44 (30.8)
Some	30 (21.0)
Very	14 (9.8)
Very much	14 (9.8)
Daily hours for taking care of the child	
Less than 2,5 hours	43 (30.1)
2,6-5 hours	51 (35.7)
5,1-7,5 hours	24 (16.8)
7,6 -10 hours	10 (7.0)
More than 10 hours	15 (10.5)
Social support scale, mean (SD)	2.30 (0.69)
Child under treatment with medicine	70 (49.0)
Mother with health problem	83 (58.0)

found that mothers with higher educational level had lower scores on Reframing. Also, increased daily hours for taking care of the child and the children's treatment were associated with lower scores on Reframing. The R<sup>2</sup> of the model was 0.13. Higher affection of family's social life due to the children was associated with lower scores on Mobilizing Family to Acquire and Accept Help in multiple analyses. Furthermore, increased social support was found to be associated with greater scores on Mobilizing Family to Acquire and Accept Help and the R2 of the model was 0.11. Increased age of the child and increased number of children in the family were found to be associated with greater scores on Seeking Spiritual Support. Additionally, married mothers had higher score

on Seeking Spiritual Support and the R<sup>2</sup> of the model was 0.15. Regarding Acquiring Social Support, increased social support was found to be associated with greater scores (R<sup>2</sup>=0.08) and it was also found to be associated with greater scores on Passive Appraisal dimension (R<sup>2</sup>=0.09). Mothers with higher educational level had lower scores overall on F-COPES dimension, while increased age of the child was found to be associated with greater scores on overall F-COPES and the R2 of the model was 0.16.

Correlation analysis between F-COPES and PSI dimensions and CES-D (table 4) revealed that Reframing was significantly negatively correlated with Parental Distress, while Parent-Child Dysfunctional Interaction was significantly positively correlated with Passive Appraisal. Passive Appraisal was the only F-COPES dimension that was found to be significantly positively correlated with depression. The aforementioned correlations were significant but low. Adjusting the analysis for demographic factors the partial correlations between Passive Appraisal and depression (r=0.19, p=0.038), between Reframing and Parental Distress (r=-0.20, p=0.031) and between Passive Appraisal and Parent-Child Dysfunctional Interaction (r=-0.25, p=0.005), remained significant.

## **Discussion**

The present study examined the coping strategies used by mothers of children with ASD, as well as the associations between maternal stress, depressive symptoms and coping strategies. Coping strategies were related to family demographic characteristics maternal stress, depressive symptoms, as well as characteristics specific to child age and to the disorder.

Examining the relationship between coping strategies and marital status, seeking spiritual support was significantly associated with marital status, that is married mothers scored higher in the aforementioned subscale, while increased number of children in the family predicted higher maternal spiritual support. Also, older child's age was found to be associated with a greater search for spiritual support. As both children and mothers get older it is more likely for mothers to experience an existential crisis and anxiety about their child's future, that would lead them to seek spiritual support.

An interesting finding of the present study was that mothers of higher education level used the coping strategy of reframing less often and had a lower score on overall F-COPES. It seems that higher educated parents may have higher expectations for their child's development and at the same time be aware of the nature of the disorder and the related difficulties, leading to higher levels of frustration.<sup>36</sup>

**Table 2.** Linear regression analyses results for the dependent variables Reframing, Mobilizing Family to acquire and Accept Help and Seeking Spiritual Support.

	Reframing		Mobilizing Family to Acquire and Accept Help		Seeking Spiritual Support	
	β (SE) <sup>+</sup>	р	β (SE)+	р	β (SE)+	р
Child's gender						
Boys (reference)						
Girls	0.60 (1.99)	0.767	-0.35 (1.47)	0.817	0.37 (1.36)	0.788
Child's age (years)	0.09 (0.26)	0.720	0.16 (0.19)	0.410	1.00 (0.18)	< 0.001
Mother's age (years)	-0.11 (0.19)	0.569	0.10 (0.15)	0.514	-0.09 (0.15)	0.579
Father's age (years)	0.11 (0.15)	0.482	-0.11 (0.11)	0.338	-0.02 (0.11)	0.849
Educational status						
Primary/ Middle/ High school or 2–year college						
University/ Post–graduate studies	-2.02 (0.77)	0.010	0.50 (1.41)	0.727	-0.50 (1.44)	0.731
Married						
No (reference)						
Yes	-1.77 (2.49)	0.487	0.09 (1.91)	0.962	3.80 (1.69)	0.036
Number of children in the family	1.03 (1.15)	0.381	-0.83 (0.86)	0.348	2.71 (0.91)	0.008
Number of stressful events	-0.29 (0.37)	0.441	-0.20 (0.29)	0.489	0.33 (0.30)	0.282
The presence of the child affects family's social life	0.17 (0.76)	0.825	-0.22 (0.11)	0.048	0.83 (0.59)	0.177
Daily hours for taking care the child	-0.65 (0.30)	0.029	-0.68 (0.61)	0.281	-0.98 (0.56)	0.096
Social support scale	-0.89 (1.39)	0.533	1.19 (0.39)	0.003	0.12 (1.00)	0.905
Child under treatment with medicine						
No (reference)						
Yes	-1.87 (0.86)	0.035	-0.05 (1.07)	0.963	1.16 (1.12)	0.311
Mother with health problem						
No (reference)						
Yes	2.19 (1.32)	0.115	-0.17 (1.02)	0.870	-1.14 (1.08)	0.305

<sup>†</sup>regression coefficient (Standard Error)

Increased daily hours for taking care of the child with autism, as well as child's pharmacological treatment were associated with lower scores on reframing. These two conditions might reflect a higher severity of the disorder. In line with the notion that parental stress is positively correlated with their children's behavioral problems and the severity of ASD symptoms,<sup>27</sup> it might be that the severity of child's ASD symptoms and the obligations arising from it do not leave much room for mothers to use reframing as an effective coping strategy. On the other hand, a recent report highlighted the usefulness of reframing for all levels of child behavior problems as an effective strategy, even in families with a child with severe symptomatology.<sup>37</sup>

Higher affection of family's social life due to the children was associated with lower levels of mobilizing family to acquire and accept help. At the same time, increased social support was found to be associated with greater scores on mobilizing family to acquire and accept help and acquiring social support. In cases where the social life of the family is strongly influenced by the child with autism, it is possible that the mothers have experienced stigma and rejection from the wider society. Perhaps the fear of social stigma and impending frustration prevents mothers of children with autism from accepting the help of others. On the other hand, when they have the positive social experience of receiving social support it is probably easier for them to seek and receive it again.

**Table3.** Linear regression analyses with dependent variables Acquiring Social Support, Passive Appraisal and Overall F Copes

	Acquiring Social Support		Passive Appraisal		Overall F Copes	
	β (SE)+	р	β (SE)+	р	β (SE)+	р
Child's gender						
Boys (reference)						
Girls	-0.14 (3.05)	0.963	-0.02 (1.73)	0.992	5.66 (6.89)	0.423
Child's age (years)	0.50 (0.40)	0.227	0.17 (0.23)	0.473	0.20 (0.09)	0.026
Mother's age (years)	0.34 (0.34)	0.324	-0.03 (0.19)	0.874	-0.10 (0.67)	0.880
Father's age (years)	0.04 (0.26)	0.872	0.07 (0.15)	0.648	-0.02 (0.51)	0.970
Educational status						
Primary/ Middle/ High school or2–year college						
University/ Post-graduate studies	0.46 (3.21)	0.888	-1.16 (1.83)	0.535	-5.50 (2.46)	0.028
Married						
No (reference)						
Yes	2.28 (3.78)	0.553	1.60 (2.15)	0.466	3.01 (8.60)	0.731
Number of children in the family	0.66 (2.04)	0.752	-0.08 (1.16)	0.945	5.47 (3.94)	0.184
Number of stressful events	0.26 (0.67)	0.708	0.13 (0.38)	0.744	0.51 (1.28)	0.695
The presence of the child affects family's social life	-2.58 (1.34)	0.070	-0.31 (0.75)	0.687	0.09 (2.65)	0.974
Daily hours for taking care the child	1.02 (1.25)	0.427	0.01 (0.71)	0.984	-2.79 (2.74)	0.324
Social support scale	2.15 (0.89)	0.017	-1.00 (0.43)	0.029	2.82 (1.81)	0.124
Child under treatment with medicine						
No (reference)						
Yes	0.68 (2.50)	0.790	0.65 (1.43)	0.653	2.88 (4.83)	0.560
Mother with health problem						
No (reference)						
Yes	0.97 (2.45)	0.696	0.55 (1.37)	0.693	2.12 (4.62)	0.652

<sup>†</sup>regression coefficient (Standard Error); F–COPES: Family Crisis Oriented Personal Scales

 Table 4. Correlation coefficients between F-COPES and PSI-SF dimensions, CES-D.

	PSI				CES-D
	Defensive Responding	Parental Distress	Parent-Child Dysfunctional Interaction	Difficult Child	
F-COPES					
Reframing	15	23*	11	01	16
Mobilizing Family to Acquire and Accept Help	.03	02	13	.02	11
Seeking Spiritual Support	05	03	04	.06	14
Acquiring Social Support	.02	02	.07	.03	11
Passive Appraisal	.11	.07	.21*	.17	.20*
Overall F Copes	.00	06	.04	.11	13

<sup>\*</sup>p<.05; \*\*p<.01; \*\*\*p<.001; F-COPES: Family Crisis Oriented Personal Scales; PSI-SF: Parenting Stress Index Short-Form; CES-D: Center for Epidemiologic Studies Depression Scale

Examining the relationship between coping strategies and parental distress, reframing was found to be negatively correlated with parental distress. This is in accordance with findings from previous studies, <sup>39,40</sup> which have shown that positive reframing of potentially traumatic and stressful events could be an effective coping strategy under extreme conditions, where direct actions for stress reduction cannot be applied. <sup>34</sup> In addition, in a recent study <sup>37</sup> reframing was one of the coping strategies associated with lower parental stress.

We also found that parent-child dysfunctional interaction was positively correlated with passive appraisal. It is possible for mothers of children with autism who have difficulty interacting with them, to resort to a passive assessment strategy in order to avoid overreacting to their child's problem behavior, which could further complicate the interaction between each other. In addition, it was found that increased social support was associated with lower levels of passive appraisal as a coping strategy. Perhaps, mothers who receive increased social support are more likely to receive the psychological and emotional help they need, in order to take a more proactive approach to the problems arising from their child's disorder. Moreover, the present study showed that passive appraisal was positively correlated with depression. Dunn and his colleagues<sup>40</sup> examined moderators of stress on parents of children with autism and found that increased use of avoidance and escape as coping methods corresponded to increased depression. Also, increased use of avoidance and escape corresponded to increased social isolation, while increased use of positive reappraisals corresponded to decreased social isolation.

#### References

- American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. American Psychiatric Publishing, Arlington, VA, 2013, doi:10.1176/appi.books.9780890425596
- Ooi KL, Ong YS, Jacob SA, Khan, TM. A meta-synthesis on parenting a child with autism. *Neuropsychiatr Dis Treat* 2016, 12: 745–762, doi: 10.2147/NDT.S100634
- 3. Benevides TW, Lee J, Nwosu NAO, Franks J. Understanding the family impact of autism spectrum disorder in a racially and ethnically diverse sample: findings from the national survey of children with special health care needs. *Matern Child Health J* 2019, 23:951–960, doi: 10.1007/s10995-018-02724-x
- 4. Chan KKS, Lam CB, Law NCW, Cheung RYM. From child autistic symptoms to parental affective symptoms: A family process model. *Res Dev Disabil* 2018, 75:22–31, doi: 0.1016/j.ridd.2018.02.005
- 5. Dovgan K, Mazurek MO. Impact of multiple co-occurring emotional and behavioural conditions on children with autism and their families. *J Appl Res Intellect Disabil* 2019, 32: 967–980, doi: 10.1111/jar.12590
- Karst JS, Van Hecke AV. Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation.

To our knowledge, the present study is the first to explore coping strategies in Greek families having a child with ASD; nonetheless, it has a number of limitations. First, the sample was composed exclusively by mothers and the paternal coping strategies have not been explored. However, mothers are usually the primary caregivers of children in Greek culture and seem to be the ones that shoulder a heavy burden when rising a child with ASD.24 Second, the majority of children were boys. The 3.5:1 male: female ratio, though is the usual ratio reported for children with ASD.41 Third, maternal emotional state was measured only by a self-report questionnaire, the CES-D. Nevertheless, this is a highly sensitive tool, and has been used to detect depression in the general population and has been used in Greek populations.<sup>29</sup> In the future multi-informant assessments could also be used in order to obtain more measures of the predictor variables. Finally, the study has a cross-sectional design meaning that we cannot draw conclusions about causality.

To conclude, our findings illustrate the coping strategies implemented by mothers of children with ASD and the importance of the available social support. Interventions based on a Cognitive-Behavior Therapy approach help parents of children with ASD develop reframing strategies, dispirit them from using avoidance and escape coping styles and encourage them to use a more proactive, problem-focused coping strategies. Also, increasing the quality of social support networks in the environment of the family with a child with an ASD diagnosis, could help mothers to effectively cope with the distress arising from their child's disorder.

- Clin Child Fam Psychol Rev 2012, 15: 247-277, doi:10.1007/s10567-012-0119-6
- 7. Kogan MD, Strickland BB, Blumberg SJ, Singh GK, Perrin GM, Van Dyck PCA. A national profile of the health care experiences and family impact of autism spectrum disorder among children in United States. *Pediatrics* 2008, 122: e1149-1158, doi:10.1542/peds.2008-1057
- 8. Petrou MA, Soul A, Koshy B, McConachie H, Parr R J. The impact on the family of the co-existing conditions of children with autism spectrum disorder: Impact of co-existing conditions in ASD. *Autism Res* 2018, 11: 776-787, doi: 10.1002/aur.1932
- 9. Dale E, Jahoda A, Knott F. 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* 2006, 10: 463-479, doi: 10.1177/1362361306066600
- Poslawsky El, Naber F, Daalen VE, Engeland VH. Parental reaction to early diagnosis of their children's autism spectrum disorder: An exploratory study. *Child Psychiatry Hum Dev* 2014, 45:294–305, doi: 10.1007/s10578-013-0400-z
- Estes A, Olson E, Sullivan K, Greenson J, Winter J, Dawson G, et al. Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain Dev* 2013, 35:133–138, doi: 10.1016/j.braindev.2012.10.004

- Sharpley C, Bitsika V, Efremidis B. Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *J Intellect Dev Disabil* 1997, 22:19–28, doi: 10.1080/13668259700033261
- Altiere J, Von Kluge S. Family functioning and coping behaviors in parents of children with autism. J Child Fam Stud 2009, 18:83–92, doi: 10.1007/s10826-008-9209-y
- Benson PR. Coping, distress, and well-being in mothers of children with autism. Res Autism Spectr Disord 2010, 4: 217-228, doi: 10.1016/j. rasd 2009.09.008
- Benson PR, Karlof KL. Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. J Autism Dev Disord 2009, 39: 350-362, doi: 10.1007/s10803-008-0632-0
- Schlebusch L, Dada S. Positive and negative cognitive appraisal of the impact of children with autism spectrum disorder. Res Autism Spectr Disord 2018, 51: 86–93, doi: 10.1016/j.rasd.2018.04.005
- Barker ET, Hartley SL, Seltzer MM, Floyd F J, Greenberg JS, Orsmond GI. Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Dev Psychol* 2011, 47:551–561, doi: 10.1037/ a0021268
- Bennett T, Boyle M, Georgiades K, Georgiades S, Thompson A, Duku E et al. Influence of reporting effects on the association between maternal depression and child autism spectrum disorder behaviors. J Child Psychol Psychiatry 2012, 53: 89–96, doi: 10.1111/j.1469-7610.2011.02451.x
- Ingersoll B, Hambrick DZ. The relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. Res Autism Spectr Disord 2011, 5:337–344, doi: 10.1016/j.rasd.2010.04.017
- Weitlauf AS, Vehorn AC, Taylor JL, Warren ZE. Relationship satisfaction, parenting stress, and depression in mothers of children with autism. Autism 2014, 18:194–198, doi: 10.1177/1362361312458039
- 21. Zablotsky B, Bradshaw CP, Stuart EA. The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. *J Autism Dev Disord* 2013, 43:1380–1393, doi: 10.1007/s10803-012-1693-7
- 22. Montes G, Halterman JS. Psychological functioning and coping among mothers of children with autism: A population-based study. *Pediatrics* 2007, 119: 1040–1046, doi: 10.1542/peds.2006-2819
- 23. Karaivazoglou K, Papadaki E, Iconomou G, Touliatos G, Kotsopoulos S, Assimakopoulos K. Psychological distress and health-related quality of life in parents of children referred to an outpatient service for children with developmental disorders. *Australas Psychiatry* 2019, 27: 152–156, doi:10.1177/1039856218815754
- 24. Ntre V, Papanikolaou K, Triantafyllou K, Giannakopoulos G, Kokkosi M, Kolaitis G. Psychosocial and financial needs, burdens and support, and major concerns among Greek families with children with autism spectrum disorder (ASD). *Intern J Caring Sci* 2018, 11 985-995.
- 25. Pattini E, Carnevali L, Troisi A, Matrella G, Rollo D, Fornari M, Sgoifo A. Psychological characteristics and physiological reactivity to acute stress in mothers of children with autism spectrum disorder. *Stress Health* 2019, 35:421–431, doi: 10.1002/smi.2870
- 26. Lai WW, Oei TPS. Coping in parents and caregivers of children with autism spectrum disorders (ASD): A review. *Rev J of Autism Dev Disord* 2014, 1: 207–224, doi: 10.1007/s40489-014-0021-x

- 27. Miranda A, Mira A, Berenguer C, Rosello B Baixauli I. Parenting stress in mothers of children with autism without intellectual disability. Mediation of behavioral problems and coping strategies. *Front Psychol* 2019, 10:464, doi: 10.3389/fpsyg.2019.00464
- Radloff LS. The CES-D scale: A self-report depression scale for research in the general population. Appl Psychol Meas 1997, 1:385–401, doi:10.1177/014662167700100306
- 29. Fountoulakis K, lacovides A, Kleanthous S, Samolis S, Kaprinis SG, Sitzoglou K et al. Reliability, validity and psychometric properties of the Greek translation of the Center for Epidemiological Studies-Depression (CES-D) Scale. *BMC Psychiatry* 2001, 1: 1-8, doi: 10.1186/1471-244X-1-6
- 30. McCubbin Hl, Olson D, Larsen A. Family crisis oriented personal evaluation scale. In McCubbin Hl, Thompson Al, McCubbin MA (eds) Family assessment: Resiliency, coping and adaptation Inventories for research and practice. Madison: University of Wisconsin System; 1996
- Gouva M, Dragioti E, Konstanti Z, Kotrotsiou E, Koulouras V. Translation and Validation of a Greek version of the Family Crisis Oriented Personal Evaluation Scales (F- COPES). *Interscientific Health Care* 2016, 8:64–72
- 32. Abidin RR. Parenting Stress Index: Professional Manual. 3rd ed. Psychol Assess Resources, Odessa, FL, 1995
- Haskett ME, Ahern LS, Ward CS, Allaire JC. Factor structure and validity
  of the parenting stress index-short form. J Clin child Adolesc Psychol
  2006, 35:302–312, doi:10.1207/s15374424jccp3502\_14
- 34. Hastings RP, Kovshoff H, Brown T, Ward NJ. Espinosa FD, Remington B. Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism* 2005, 9: 377–391, doi: 10.1177/1362361305056078
- 35. Hadjicharalambous D, Demetriou L. Investigating the influences of parental stress on parents parenting practices. *Int J Sci Acad Res* 2021, 2:1140–1148
- 36. Dabrowska A, Pisula E. Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *J Intellect Disabil Res* 2010, 54:266–280, doi: 10.1111/j.1365-2788. 2010.01258 x
- 37. Reed P. Child behavior problems moderate effectiveness of coping strategies except for reframing for mothers of children with ASD. *Res Autism Spectr Disord* 2020, 76: 101589, doi: 10.1016/j. rasd.2020.101589
- 38. Loomes R, Hull L, Polmear W, Mandy WPL. What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *J Am Acad Child Adolesc Psychiatry* 2017, 56:466–474, doi: 10.1016/j.jaac.2017.03.013
- Papadopoulos Ch, Lodder A, Constnantinou G, Randhawa G. Systematic review of the relationship between autism stigma and informal caregiver mental health. J Autism and Dev Disord 2019, 49: 1665–1685, doi: 10.1007/s10803-018-3835-z
- 40. Dunn ME, Burbine T, Bowers CA, Tantleff-Dunn S. Moderators of stress in parents of children with autism. *Community Ment Health J* 2001, 37: 39–52, doi: 10.1023/a: 1026592305436
- 41. Loomes R, HullL, Polmear W, Mandy L. What is the male-to-female ratio in autism spectrum disorder? A systemic review and meta-analysis. *J Am Acad Child Adolesc Psychiatr* 2017, 56:466–474, doi: 10.1016/j. jaac.2017.03.013

# Ερευνητική εργασία

# Στρατηγικές αντιμετώπισης των μητέρων με παιδιά με διαταραχές του φάσματος του αυτισμού: Η σχέση με το μητρικό στρες και την κατάθλιψη

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# ΠΕΡΙΛΗΨΗ

Η ύπαρξη παιδιού με αυτισμό έχει ισχυρό αντίκτυπο σε ολόκληρη την οικογένεια και ειδικά στις μητέρες, οι οποίες είναι συνήθως οι κύριοι φροντιστές των παιδιών αυτών. Οι γονείς παιδιών με αυτισμό αναφέρουν περισσότερα προβλήματα ψυχικής υγείας, σε σύγκριση με τους γονείς παιδιών με άλλες αναπτυξιακές αναπηρίες ή γονείς παιδιών φυσιολογικής ανάπτυξης. Οι γονικές στρατηγικές αντιμετώπισης άγχους μπορεί να διαδραματίσουν σημαντικό ρόλο όταν οι γονείς έρχονται αντιμέτωποι με στρεσογόνες καταστάσεις κατά τη διάρκεια της ανάπτυξης του παιδιού. Σκοπός της παρούσας έρευνας ήταν να διερευνήσει τις στρατηγικές αντιμετώπισης (διαχείριση δύσκολων καταστάσεων και αλληλεπίδραση με το περιβάλλον) σε μητέρες με παιδιά με αυτισμό και τη σχέση αυτών των στρατηγικών με το μητρικό στρες και την κατάθλιψη. Στην παρούσα μελέτη συμμετείχαν 143 μητέρες (μέση ηλικία 42,7 ετών) παιδιών με αυτισμό (6–17 ετών) που είχαν απευθυνθεί στο Ειδικό Ιατρείο Διαταραχών Φάσματος Αυτισμού της Πανεπιστημιακής Παιδοψυχιατρικής Κλινικής στο Γενικό Νοσοκομείο Παίδων. Οι συμμετέχουσες στην έρευνα συμπλήρωσαν τα ακόλουθα ερωτηματολόγια: Ερωτηματολόγιο δημογραφικών στοιχείων, την Κλίμακα κατάθλιψης (Center for Epidemiologic Studies Depression Scale, CES-D), την Κλίμακα στρατηγικών αντιμετώπισης (Family Crisis Oriented Personal Scales, F-COPES) και το ερωτηματολόγιο γονεϊκού στρες (Parenting Stress Index Short-Form, PSI-SF). Οι μητέρες με υψηλότερο μορφωτικό επίπεδο σημείωσαν σημαντικά χαμηλότερη βαθμολογία στην υποκλίμακα «αναπλαισίωση» του F-COPES και στη συνολική βαθμολογία του F-COPES. Οι αυξημένες καθημερινές ώρες που αφορούσαν στη φροντίδα του παιδιού και η φαρμακευτική αγωγή του παιδιού ήταν επιπρόσθετοι παράγοντες που συσχετίζονταν σημαντικά με χαμηλότερες βαθμολογίες στην υποκλίμακα «αναπλαισίωση». Η υποκλίμακα αυτή συσχετίστηκε επίσης αρνητικά με τα επίπεδα γονικής δυσφορίας, ενώ η υποκλίμακα «παθητική αξιολόγηση» του F-COPES συσχετίστηκε θετικά με τα καταθλιπτικά συμπτώματα των μητέρων. Οι χαμηλότερες βαθμολογίες σχετικά με την κινητοποίηση της οικογένειας για απόκτηση και αποδοχή βοήθειας συσχετίστηκαν με σοβαρή επιβάρυνση στην οικογενειακή ζωή. Οι στρατηγικές αντιμετώπισης των μητέρων παιδιών με αυτισμό σχετίζονται με διάφορους παράγοντες όπως τα προσωπικά χαρακτηριστικά των φροντιστών, τη θεραπεία των παιδιών και τα οικογενειακά χαρακτηριστικά. Οι επαγγελματίες ψυχικής υγείας είναι σημαντικό να εξετάζουν προσεκτικά παράγοντες που μπορεί να ενισχύσουν τις στρατηγικές αντιμετώπισης, οι οποίες βοηθούν τις μητέρες να διαχειριστούν τις προκλήσεις που συναντούν, όταν μεγαλώνουν παιδί με αυτισμό.

ΛΕΞΕΙΣ ΕΥΡΕΤΗΡΙΟΥ: Διαταραχές φάσματος αυτισμού, στρατηγικές αντιμετώπισης, κατάθλιψη, γονεϊκό στρες

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