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(RESEARCH ARTICLE)



# Health promotion for parents of children with autism spectrum disorder

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#### **Abstract**

Research has shown that parents of children with autism spectrum disorder (ASD) experience high levels of anxiety. The type of disorder and demographic characteristics of the parents can affect anxiety levels. However, parent counseling programs can have a positive impact on parents' effectiveness in their role, which can positively affect their mental health. This study aims to investigate the anxiety levels of parents of children with autism, the impact of counseling programs on parental anxiety, and how demographic characteristics of the parents can affect anxiety levels. The sample consisted of 101 parents of children with ASD attending primary schools across Greece. The data for this study was collected through a questionnaire which included demographic information, questions about the counseling intervention, and the Parenting Stress Index Short-Form scale. The results indicated that the overall level of parental stress was relatively high and that the parents' demographic characteristics influenced the subscales of the Parenting Stress scale. The parents with higher education levels experienced the highest levels of distress, and the highest levels of dysfunctional interaction were observed in parents over 40 years of age and in divorced or unmarried parents. Nearly half of the participants in the study had undergone counseling therapy, which had a predominantly positive impact on improving parent-child interaction. The findings suggest that demographic factors significantly affect levels of parental anxiety and that parents who expressed a desire to enhance their role as caregivers through counseling therapy also reported higher levels of anxiety. Overall, the results highlight the potential benefits of counseling therapy in addressing dysfunctional parent-child interactions and improving parental well-being.

Keywords: Dyslexia; SEN (Special Educational Needs); Comorbidity; Intervention; Inclusion

#### 1. Introduction

Families who have members with disabilities experience elevated levels of stress, which is influenced by the nature of the disorder. Research shows that families of children diagnosed with developmental and behavioural disorders experience the highest levels of stress as compared to those with children diagnosed with chronic medical conditions (Gupta, 2007). Specifically, parents of children with autism spectrum disorders experience high levels of stress, which leads to poor family functioning and lower levels of emotional well-being when compared to parents of children with different disabilities.

Parents of children with ASD tend to rely on emotional coping strategies instead of problem-focused ones (Samadi, Mcconkey, & Kelly, 2013). However, through a short-term counselling program, they can acquire the necessary resources to become effective in their role. Counselling can help parents understand their child's needs and disorders, explore their feelings, and enhance their self-efficacy, which in turn can reduce stress levels, as low self-efficacy has been associated with high stress levels (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Hastings & Symes, 2002).

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### 2. Stress factors of parents of children with autism spectrum disorder

Research on parental stress has mostly concentrated on the connection between the stress levels of parents and the individual traits of their children (Collins, Maccoby, Steinberg, Hetherington, & Bornstein, 2000; Rivard, Terroux, Parent-Boursier, & Mercier, 2014). It seems that parents' attitudes can have an impact on their children's behavioural issues, and their children's behaviour, in turn, can affect the parents (Baker et al., 2003).

A study conducted by Keller and Honig (Keller & Honig, 2004) explored the stress factors experienced by families with school-aged children who have disabilities. The study revealed that increased parental stress is associated with child characteristics such as irritability, moodiness, and demandingness. Factors that influence parental stress include the negative attitudes of society, the increased need for care of the child with disabilities, the socioeconomic status of the family, and the failure to meet parents' expectations for their children's performance. The findings of the research showed that having a disabled child in a middle-class family does not necessarily lead to an increase in stress levels. Moreover, the gender of the parent did not play any significant role in the levels of stress experienced by the parents, nor did the dimensions that were given. However, the study found that child characteristics and family harmony were highly correlated with stress levels.

Several studies have suggested that while language and communication difficulties, as well as stereotyped behaviours, are common in children with ASD, they do not significantly contribute to parental stress (Davis & Carter, 2008; Tomanik, Harris, & Hawkins, 2004). These findings imply that it is the combination of various problems related to emotions, functioning and behaviour in ASD, combined with the pervasive developmental disorders these children face, that affects parents more than the symptoms of autism per se (Karst & van Hecke, 2012).

It has been observed that child characteristics tend to amplify the stress levels of mothers in the family. This is particularly true in cases where the children display challenging behaviours. Research conducted by Hastings et al. (Hastings, 2003) focused on how stress is experienced by each parent based on their gender. The literature suggests that mothers experience stress differently from fathers, especially in the case of children with disabilities. The study revealed that while there were no significant differences in anxiety and depression levels between the two genders, mothers reported higher stress levels than fathers. Additionally, a small sample of fathers indicated that their anxiety was influenced by their wife's depression.

Mothers who participated in a study assessing their children's behaviour and their own stress and mental health had more positive perceptions than fathers but also reported more depression. Fathers' mental health had a high correlation with mothers' depression, while maternal stress was a consequence of children's behaviour - not from adaptive behaviour or autism symptoms - but also their partner's mental health. In addition, Little (Little, 2002) argued that gender played a role in general anxiety and stress about the family. Specifically, mothers perceived higher levels of stress for individual family members and the family as a whole.

Tehee et al. (Tehee, Honan, & Hevey, 2009) found that parental involvement is a factor related to gender and stress. The study revealed that mothers of children with ASD tend to be more involved in parenting than fathers, which in turn can lead to higher levels of stress. Researchers concluded that parental involvement can be a link between parental gender and stress. Therefore, it is suggested that parental involvement can partially or completely explain the relationship between parental gender and stress.

Bebko et al. (Bebko, Konstantareas, & Springer, 1987) found that there is a correlation between the gender of the parent and the age of the child, where the mothers of older children had lower levels of stress compared to those of younger children. However, the father's stress levels did not show significant differences and were independent of the child's age. The researchers attributed this decrease in stress to mothers more readily accepting the problems faced by their child on the autism spectrum (Estes et al., 2009).

Mancil et al. (Mancil, Boyd, & Bedesem, 2009) and Gray (Gray, 2002) also confirmed that there is a strong correlation between the age of parents and their level of anxiety. As parents and children grow older, the opportunities for family support and intervention often decrease, leading to negative effects on the mental health of parents.

It appears that providing socioeconomic support is crucial for the mental health of parents who have children with autism spectrum disorder (ASD), but it doesn't seem to significantly impact the stress levels of mothers. According to a study, variables such as socioeconomic support and parenting knowledge are better indicators of parental mental health problems than child-related variables (Falk, Norris, & Quinn, 2014). Some couples even have to borrow a significant

amount of money or sell their assets to afford the expensive services that their child with autism needs (Altiere & Von Kluge, 2009).

Due to a lack of financial support mechanisms provided by the state, many parents are struggling financially. The parents of children with disorders are particularly affected as they bear the high costs of evaluations and treatments. These disorders are complex and require frequent, multidimensional interventions throughout the child's life (Lord & Bishop, 2010).

Family relationships play a crucial role in predicting stress levels. Studies have shown that mothers require more support from their partners compared to fathers and also want them to take on more responsibilities concerning their children with ASD and the household chores (Konstantareas & Homatidis, 1989).

What is more, the quality of life of parents is directly related to their family situation and, consequently, their stress levels. According to Hsiao's (Hsiao, 2018) research, parents who have a partner in their lives report less stress and a better quality of life than those who live alone with their children.

Additionally, parental education may account for a small proportion of parents' stress levels and quality of life. According to a study conducted by Hsiao in 2018 (Hsiao, 2018), parents with a bachelor's or master's degree generally have a better quality of life than those with a lower education level. Another research conducted in Bangladesh involving 80 mothers of children with autism attending a special school showed that there is no significant correlation between their education level and stress levels (Akter, Khatun, & Biswa, 2020).

#### 3. Methods

#### 3.1. Participants

The study involved 101 parents of children with ASD attending Primary Education. All the participants were required to fill in a questionnaire that recorded their demographics and counselling intervention programs attended. After that, they took the Parenting Stress Index – SF scale. The results related to participant demographics are presented in Table 1.

Table 1 Demographics

Demographics	Categories	N	f %
Sex	Man	15	14.85%
	Woman	86	85.15%
Age	Up to 30	4	3.96%
	31-40	35	34.65%
	41-50	53	52.48%
	Over 51	9	8.91%
Marital status	Single - Single-parent family	2	1.98%
	Married	83	82.18%
	Divorced	16	15.84%
Education	Gymnasium	3	2.97%
	Lyceum	21	20.79%
	University	44	43.56%
	Master studies	22	21.78%
	Institute of Vocational Training	11	10.89%
Family income	Under 10,000	11	10.89%

10,000-15,000	23	22.77%
15,000-20,000	15	14.85%
20,000-25,000	24	23.76%
Over 25,000	28	27.72%

Table 2 Parent counseling therapy

	Categories	N	f %
Have you completed a parent counseling program after your child's autism diagnosis?	No	51	50.50%
	Yes	50	49.50%
Did you attend a group or individual parenting counseling therapy program?	Individual	41	82.00%
	Group	9	18.00%
Was the program implemented by a public or private body?	Public	8	16.00%
	Private	42	84.00%
Did any other family members participate in the counseling therapy program?	No	19	38.00%
	Yes	31	62.00%
Do you feel that your role as a parent of a child with autism has been strengthened	No	2	4.08%
through the counseling therapy?	Yes	47	95.92%
Do you feel that your role as a partner has been strengthened through the counseling	No	18	36.00%
therapy?	Yes	32	64.00%

### 3.2. Measuring instruments/Intervention programs

To conduct the research, we administered a closed-ended questionnaire to gather demographic data and counselling treatment information. In addition, we used the Parenting Stress Index – Short Form scale, which consists of four subscales: Parental Distress, Parent-Child Dysfunctional Interaction, Difficult Child, and Defensive Responding. This scale was developed by Reitman et al. (Reitman, Currier, & Stickle, 2002) and Haskett et al. (Haskett, Ahern, Ward, & Allaire, 2006).

The questionnaire used in the research initially requested the parents' consent to participate. Afterwards, the parents were asked about their demographics, including their gender, age, family income, marital status, and educational level. Following this, the parents were asked if they had completed a parent counselling treatment program. If they answered positively, they were asked about the type of program, whether other family members also participated, and how they felt the program enhanced their role as a parent and fellow parent. Finally, the parents answered the Parenting Stress Index – SF weighted scale in Greek.

The validity and reliability of the scale used in researching parental stress experienced by parents of children with disabilities have been established, with a Cronbach's alpha of 0.92 (Derguy, M'Bailara, Michel, Roux, & Bouvard, 2016). Similar research conducted in Greece has also shown good internal stability and consistency in the subscales. In our present study, the reliability of the scale was excellent, with a Cronbach's alpha of 0.936.

#### 3.3. Aim

This research aimed to investigate the effectiveness of counselling intervention programs for parents of children with ASD in reducing anxiety and improving their parenting skills.

#### 4. Results

In terms of parental stress overall, the average rating was 92.12 with a standard deviation of 23.49. The subscale "Parental Distress" showed slightly higher values than the average score (M=31.41, STD.=9.72). On the other hand, the subscale "Dysfunctional Parent-Child Interaction" had a lower rating (M=29.04, STD.=7.92), while the parents scored relatively higher values in the "Difficult Child" subscale (M=31.66, STD.=9.29). Additionally, the "Defensive Responding" subscale showed a score greater than 10 (M=19.57, STD.=5.88), indicating that the parents' defensive response is considered low.

**Table 3** Means and standard deviations for parenting stress

	Parental Distress	Parent-Child Interaction	Dysfunctional	Difficult Child	Defensive Responding
Mean	31.41	29.04		31.66	19.57
Standard Deviation	9.72	7.92		9.29	5.88

#### 4.1. Correlation in terms of counselling programs

### 4.1.1. Completion of parent counselling program

The study analyzed the correlation between counselling programs and the completion of the parent counselling program. Table 4 indicates that there was no statistical significance in means for the factors related to the completion of the parent counselling program ( $p \ge 0.250$ ).

Table 4 Factors \*Completion of parent counselling program, Independent samples t-test

Factor		Completion of program	of	parent	counselling	M	t	df	p- value
Total stress		No				2.58	0.551	99	0.610
						2.51			
Parental Distress		No				2.71	1.096	99	0.276
						2.53			
Parent-Child	Dysfunctional	No				2.47	1.158	99	0.250
Interaction		Yes				2.30			
Difficult Child		No				2.57	-	99	0.360
		Yes				2.71	0.919		

### 4.2. Type of program followed

Moreover, as shown in Table 5, a statistically significant difference of means was observed for the factor "Dysfunctional parent-child interaction" at a 10% significance level when considering the type of program followed by the parents (t (28,446) = 1.863), p=0.073).

**Table 5** Factors \* Type of program, Independent Samples t-test

Factor	Type of program	M	t	df	p-value
Total stress	Individual	2.57	1.235	48	0.223
	Group	2.27			
Parental Distress	Individual	2.58	0.865	48	0.391
	Group	2.31			
Parent-Child Dysfunctional Interaction	Individual	2.36	1.863	28.446	0.073
	Group	2.06			
Difficult Child	Individual	2.77	1.201	48	0.236
	Group	2.45			

Specifically, Table 5 shows that in the factor "Dysfunctional parent-child interaction" the average of individuals who followed an individual program (M=2.36) was statistically greater (p=0.073) than the average of individuals who followed a group program (M=2.06).

### 4.3. Family participation in the program

On the other hand, there was no statistically significant difference in means observed for the factors regarding family participation in the program ( $p \ge 0.238$ ), as per Table 6.

**Table 6** Factors \* Family participation in the program, Independent Samples t-test

Factor	Family participation in the program	M	t	df	p-value
Total stress	No	2.63	0.972	48	0.336
	Yes	2.44			
Parental Distress	No	2.67	0.898	48	0.373
	Yes	2.44			
Parent-Child Dysfunctional Interaction	No	2.45	1.196	48	0.238
	Yes	2.21			
Difficult Child	No	2.77	0.430	48	0.669
	Yes	2.68			

### 4.4. Strengthening of the parent's role through counselling

Table 7 shows a statistically significant difference of means at a 10% level of significance for the factor "Dysfunctional parent-child interaction" regarding the strengthening of the parent's role through counselling (t(47) = 1.811), p=0.077).

**Table 7** Factors \* Strengthening of the parent's role through counselling, Independent Samples t-test

Factor	Strengthening of the parent's role through counselling	M	t	df	p- value
Total stress	No	3.08	1.314	47	0.195
	Yes	2.47			
Parental Distress	No	3.29	1.352	47	0.183

		Yes	2.47			
Parent-Child Dy	Dysfunctional	No	3.08	1.811	47	0.077
Interaction		Yes	2.23			
Difficult Child		No	2.88	0.326	47	0.746
		Yes	2.70			

Specifically, Table 7 indicates that in the category of "Dysfunctional Parent-Child Interaction," individuals who felt that counselling strengthened their role as a parent had a lower statistical average (M=2.23) than those who felt that counselling did not improve their role (M=3.08), with a p-value of 0.077.

### 4.5. Counselling and strengthening the role of the partner

Finally, no statistically significant difference in means was found concerning the impact of counselling on strengthening the role of the partner ( $p \ge 161$ ) (Table 8).

Table 8 Factors \* Counselling and strengthening the role of the partner, Independent Samples t-test

Factor		Counselling and strengthening the role of the partner	M	Т	df	p- value
Total stress		No	2.64	1.008	48	0.319
		Yes	2.44			
Parental Distress		No	2.75	1.425	48	0.161
		Yes	2.40			
Parent-Child	Dysfunctional	No	2.39	0.694	48	0.491
Interaction		Yes	2.25			
Difficult Child		No	2.77	0.427	48	0.671
		Yes	2.68			

### 5. Discussion – the ICT's role

Finally, we emphasize the importance of all digital technologies in the field of education and in ADHD training. These technologies are highly effective and productive and facilitate and improve assessment, intervention, and educational procedures through mobile devices that bring educational activities anywhere (A. Drigas, Dede, & Dedes, 2020; Politi-Georgousi & Drigas, 2020; Stathopoulou, Karabatzaki, Tsiros, Katsantoni, & Drigas, 2019), various ICTs applications that are the main supporters of education (Bravou & Drigas, 2019; Athanasios Drigas & Petrova, 2014; Ioannna, Agathi, & Driga, 2023; Stathopoulou, Spinou, & Driga, 2023; Stathopoulou, Spinou, & Driga, 2023; Stathopoulou, Temekenidou, Driga, & Dimitriou, 2022; Theodorou, 2016; Xanthopoulou, Kokalia, & Drigas, 2019), and AI, STEM, Games and ROBOTICS (Bravou, Oikonomidou, & Drigas, 2022; E. Chaidi, Kefalis, Papagerasimou, & Drigas, 2021; I. Chaidi & Drigas, 2022; Demertzi, Voukelatos, Papagerasimou, & Drigas, 2018; Lytra & Drigas, 2021; Ntaountaki et al., 2019) that raise educational procedures to new performance levs. In addition, the development and integration of ICTs with theories and models of metacognition, mindfulness, meditation, and the development of emotional intelligence (Bamicha & Drigas, 2022; I. Chaidi & Drigas, 2020; Athanasios Drigas, Mitsea, & Skianis, 2021a, 2021b, 2022b, 2022a; Athanasios Drigas & Papoutsi, 2021: Athanasios Drigas, Papoutsi, & Skianis, 2021: Athanasios Drigas & Sideraki, 2021: Galitskava & Drigas, 2021; Karyotaki, Bakola, Drigas, & Skianis, 2022; Mitsea, Drigas, & Skianis, 2022a), as well as with environmental factors and nutrition (Athanasios Drigas, Karyotaki, & Skianis, 2017; Karyotaki & Drigas, 2016; Mitsea, Drigas, & Skianis, 2022c, 2022b), accelerates and improves educational practices and results more than those, particularly in minority children with ADHD, treating domain and its practices like assessment and intervention.

#### 6. Conclusion

The survey results revealed that parents' overall stress levels are higher than the norm, with significant differences and deviations in their responses. Furthermore, it was discovered that parents feel they have sacrificed more than anticipated due to their role. Specifically, parents reported that their child takes a longer time to adjust to new things and does not seem to learn as quickly as other children, which causes dysfunctional interactions to a greater extent.

In terms of difficulty, parents of above-average children reported that their child reacts strongly to situations they don't like, and it's more challenging to get them to do something or stop doing something than they expected. Parents had mixed opinions about their difficult child. They mostly agreed that their child was challenging, but they were neutral about their child crying and whining more than other children and being in a bad mood. They disagreed on statements that their child was more of a problem than expected and doing things that bothered them too much.

The above results appear to agree with the literature which suggests that parents of children with ASD experience high levels of stress and lower levels of emotional well-being.

There was no significant statistical difference found between the parents who completed a counselling treatment program and those who did not, concerning the results related to counselling. These findings align with the study conducted by Elfert & Mirenda (Elfert & Mirenda, 2015), in which it was observed that parental stress was not associated with the implementation of a counselling program for parents of children with ASD, despite having a positive perception of the program after its completion.

According to research, the type of program parents attend correlates with how they view their relationship with their child. It was found that parents who attended group programs had better results in improving their relationship with their children. The group program was beneficial in increasing parents' understanding of their children's challenges and how they can support them at all levels. (McAleese, Lavery, & Dyer, 2014) also found that the group program helped parents develop strategies to support children with ASD.

After completing the counselling treatment program, most parents reported that it had strengthened their roles as parents and partners. The counselling process helped them gain a better understanding of their child's developmental stages, situations related to ASD, and their child's unique qualities and motivations. As a result, the counselling goals were effectively achieved through this process.

Furthermore, those who responded positively about feeling empowered as parents had a more positive perception of their relationship with their child, as indicated by significantly lower scores on the "Dysfunctional Parent-Child Interaction" subscale. Counselling parents of children with ASD provides them with an opportunity to explore their emotions about their child and gain a better understanding of the disorder's needs.

### Compliance with ethical standards

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Disclosure of conflict of interest

The Authors proclaim no conflict of interest.

Statement of informed consent

Informed consent was obtained from all individual participants included in the study.

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