

## **Factors of resilience of mothers with children with Autism Spectrum Disorder**

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### **Abstract**

In this study, the resilience of mothers with children diagnosed with Autism Spectrum Disorder (ASD) was investigated and compared to the resilience of mothers with typically developing children. The factors "mother's age", "educational level" and "number of children" were examined to determine if they influence the resilience of the two groups of mothers. Resilience was assessed using the Resilience Scale (RS) by Wagnild & Young (1993). The study involved 172 mothers of children with ASD and 153 mothers of typically developing children. The results showed that mothers of children on the autism spectrum are less resilient than mothers of typically developing children. Additionally, the effect of mother's age and educational level on resilience was confirmed only for mothers with children with ASD. The number of children in the family did not differentiate the results. In conclusion, the need for psychological empowerment of mothers with children with ASD was identified.

**Keywords:** resilience, Autism Spectrum Disorder, mothers, children

### **Introduction**

Resilience has been a field of intensive research in recent years, both in the general population and among populations facing adversity, such as refugees, prisoners, parents of individuals with special needs, etc. It is a multidimensional concept, which has evolved through various phases of research, starting with its measurement and definition, progressing to understanding the processes that contribute to it and ending up with integrated approaches that combine genetic, neurobehavioral and statistical analyses (Bonanno & Diminich, 2013). It refers to an individual's ability to maintain or restore their mental health and to adapt positively to difficult and stressful situations (Singh & Kumar, 2022). It is not a trait one is born with, but rather something that can be developed throughout a person's life.

Often, resilience is "built" after experiences of intense emotional pain, but this does not mean that someone who has developed it will not feel discomfort and sadness or will not face other difficulties (American Psychological Association [APA], 2020). The development of resilience has multiple benefits. It increases a sense of optimism, self-perception and self-confidence, allowing individuals to better cope with life's challenges. Resilient people have more energy and are less prone to stress and depression. Additionally, it helps develop self-efficacy and self-control, mentally empowering individuals to overcome past traumatic experiences. Finally, resilient people create positive and constructive relationships with others, do not hesitate to seek and offer help, develop empathy and view changes as challenges for developing new skills, rather than fearing failure (Komseli et al., 2022; Reivich & Shatté, 2002).

Resilience is particularly studied in populations of people with special needs or their families, such as mothers of children on the autism spectrum. Autism Spectrum Disorder (ASD) is a lifelong developmental disorder, usually becoming apparent in the early years of a

person's life (Savvidou, 2020), with uncertain causes, possibly originating from a combination of genetic and environmental factors. Some studies link autism to chromosomal abnormalities, such as fragile X syndrome (Antoniou & Daliana, 2017; Reddy, 2005), while others point to abnormalities in areas of the brain, such as the hippocampus and amygdala (Bachevalier & Loveland, 2006; Bauman & Kemper, 1985; Happé, 2003; Tuchman, 2003). Additionally, exposure to chemicals during pregnancy has been examined as a possible factor influencing the development of autism (Talbot et al., 2015). According to Sevaslidou (2020), a study with surveys from every continent showed that ASD ranges from 1-189/10,000 individuals and autism specifically from 2.8-94/10,000 individuals, with the majority being male.

Individuals with ASD primarily face difficulties in social interaction, communication, and creative imagination. They find it difficult to understand others' expressions and emotions, they avoid eye contact and they have difficulty forming friendships (Mavroupoulou, 2011). Communication difficulties include delayed speech development, problems with articulation and language use, difficulty understanding figurative language (Galanis, 2015; Loukusa & Moilanen, 2009), or unusual characteristics such as echolalia (Prizant & Rydell, 1993, as cited in Mavroupoulou, 2011). Regarding creative imagination, they exhibit stereotypical behaviors, obsessions and resistance to changes (APA, 1987; Wing, 1996). Finally, individuals with ASD sometimes show unusual reactions to sensory stimuli. Nevertheless, not every person with ASD exhibits all of the above characteristics or to the same degree, and there are some who display exceptionally high performance in specific areas ("islets" of skills), such as mathematical calculations or art (Mavroupoulou, 2011).

The diagnosis of ASD is now conducted by DSM-V (Diagnostic and Statistical Manual of Mental Disorders, 2013), according to which three subcategories are defined based on the intensity and severity of the manifestation of the deficit behaviors of the respective disorder. Specifically, level 1 includes individuals who simply require support, level 2 includes individuals who require enhanced support, and level 3 includes individuals who require very substantial support. However, for many years, the DSM-IV (1994) was also widely used, which defined five diagnostic subcategories: autistic disorder, Asperger's syndrome, pervasive developmental disorder not otherwise specified (PDD-NOS), childhood disintegrative disorder, and Rett syndrome.

The presence of a child with ASD in the family can cause significant stress for parents and affect their resilience due to the child's substantial cognitive limitations and behavioral management challenges, which create an imbalance in the family environment (Khawar et al., 2016). A literature review by Kotera et al. (2021) found that families of children with ASD are at greater risk of developing mental health problems compared to families of typically developing children. But in general, parents of children with neurodevelopmental disorders experience higher levels of parental stress and burnout compared to parents of typically developing children (Craig et al., 2016; Alrahili, 2023). Similarly, the research by Van Bourgondien et al. (2014) showed that the levels of anxiety, depression, and burnout are higher in parents of individuals with ASD compared to parents of typically developing children or parents of children with other disabilities or chronic illnesses. On the contrary, the study by Flores-Buils and Andrés-Roqueta (2022) in Spain found that parents of children with neurodevelopmental disorders overall exhibited greater resilience than parents of typically developing children, with parents of children with ASD being more resilient compared to parents of children with Attention Deficit Hyperactivity Disorder and parents of children with Developmental Language Disorder. However, the research by Pastor-Cerezuela et al. (2021) did not find statistically significant differences in the resilience of mothers of children with ASD and mothers of typically developing children.

Specifically for mothers of individuals with ASD, research by Smith et al. (2010) showed that the levels of negative impact on their daily lives are greater than those of mothers with

typically developing children. The results of the study by Malla and Taha (2022) indicated that mothers of children with autism experience higher levels of psychological burden (anxiety, stress, depression) compared to mothers of typically developing children, and lower levels of hope and resilience.

The finding of many studies that parents of children with ASD exhibit lower resilience has led to further investigation of factors that may differentiate their resilience compared to mothers of typically developing children. One such factor is the parents' age (Kliwer & Sandler, 1992). Specifically, in the case of parents of children with ASD, some studies have found that older parents of children with ASD are more resilient (Buchholz, 2022; Malla & Taha, 2022) and exhibit a more positive disposition (Smith et al., 2010), while others have shown that the parents' age is not significantly correlated to their resilience (Flores-Buils & Andrés-Roqueta, 2022; Ghanouni & Eves, 2023; Şanlı, 2023; Sinha et al., 2016). Another factor is the parents' educational level. The research by Campbell-Sills et al. (2009) found that a higher educational level is associated with greater resilience. The same conclusion was reached by Kavaloti (2017) in a study with parents of children with autism in Greece. On the contrary, the studies by Dey and Amponsah (2020) and Şanlı (2023) showed that parents of children with special needs who have a higher level of education exhibit lower levels of resilience. Koziarz et al. (2021) concluded from their research that parents of children with autism with higher educational levels reported worse experiences in family life compared to those with less education. Additionally, Buchholz's (2022) study, which involved mothers of children with ASD, showed that the positive correlation between subscales of resilience is stronger in the group of parents without a high level of education compared to those with higher education. Another factor that has been studied in relation to resilience is the number of children in the family. The research by Flores-Buils and Andrés-Roqueta (2022), with a sample of parents of children with neurodevelopmental disorders (half of whom were parents of children with ASD), showed that the number of children in the family does not affect parents' resilience. The research of Alrahili (2023) also led to a similar result. However, the research by Smith et al. (2010) showed that a larger number of children in the family leads to more effective control of negative emotions and better adaptability (Greeff & van der Walt, 2010).

The observation that in recent years the number of individuals with ASD has increased, as well as the fact that the diagnosis of a child on the autism spectrum affects the family's life at psychological, social and economic levels, requiring the maintenance of good mental health especially for the mother to meet the caregiving demands of the child with ASD, makes it imperative to study factors that enhance resilience. The investigation of factors such as maternal age (Buchholz, 2022; Malla & Taha, 2022; Smith et al., 2010), educational level (Buchholz, 2022; Campbell-Sills et al., 2009; Dey & Amponsah, 2020; Kavaloti, 2017; Koziarz et al., 2021; Şanlı, 2023) and the number of children in the family (Greeff & van der Walt, 2010; Smith et al., 2010) led to conflicting results, necessitating further study of these factors. It is also worth noting that in the majority of studies that refer to parents, the sample was mainly mothers of children with ASD, as they primarily shoulder the demanding caregiving role for these children (Kavaloti, 2018). In this direction, this study, based on previous ones, aims to further explore findings related to maternal resilience among Greek mothers of children with ASD, comparing it with that of mothers of typically developing children. Specific research questions refer to the impact of mother's age, her educational level and the number of children in the family on maternal resilience.

### **Method**

In the present study, the quantitative research method using a questionnaire was preferred for the quick and at no cost collection of data from a large sample of mothers (Papanastasiou & Papanastasiou, 2021) and because people responding to a questionnaire share the same frame of reference, allowing for free and anonymous expression. However, a

disadvantage is that the sample may not necessarily be representative, not all the questionnaires that are sent out may be completed, while at the same time respondents' answers may not always be entirely truthful as they strive to provide socially acceptable responses. Another negative aspect is that the motivations for completing the questionnaire by each participant are unknown, which prevents verification of the validity of the responses (Papanastasiou & Papanastasiou, 2021).

The questionnaire was completed by 325 mothers in total, 172 mothers of children with ASD and 153 mothers of typically developing children. Detailed presentation of the demographic characteristics is provided in Table 1, including information on mothers' age, mothers' educational level and overall number of children for each participant, with or without a child with ASD, as well as their family and financial status. Additionally, there is information about the age and gender of the child with ASD and their diagnosis. From Table 1, it emerges that the majority of mothers are educated (have at least one degree), with a moderate annual income, married with two children. Regarding children with ASD, almost 60% of the sample, mostly children over 7 years old, were diagnosed with DSM-IV because this manual was used in the assessment centers during the last decades, while the younger children were diagnosed with a DSM-V: autism level 1 and level 2 (level 3 is not included because only two children were diagnosed in this level) . The majority of the children were boys.

**Table 1. Demographic characteristics of the participants and their children with ASD**

		Mothers of children with ASD (172 in total)		Mothers of typically developing children (153 in total)	
		N	%	N	%
<b>Age groups</b>	25-40	78	45,3	86	56,2
	41-61	94	54,7	67	43,8
<b>Number of children in the family</b>	1	42	24,4	47	30,7
	2	95	55,2	82	53,6
	3 and above	35	20,4	24	15,7
<b>Education level</b>	Graduate of Secondary Education	45	26,1	43	28,1
	University graduate	67	39	57	37,3
	Master's/PhD holder	60	34,9	53	34,6
<b>Marital status</b>	Married	131	76,1	134	87,6
	Divorced	26	15,1	12	7,8
	Widow	8	4,7	2	1,3
	Unmarried	7	4,1	5	3,3
<b>Income</b>	High	21	12,2	17	11,1
	Moderate	110	64	111	72,5
	Low	41	23,8	24	15,7
<b>Age of the child with ASD</b>	3-7	60	34,9		
	8-12	55	32		
	13-17	32	18,6		
	18 and above	25	14,5		
<b>DSM-IV &amp; DSM_V diagnosis</b>	Autistic Disorder level 1	27	15,7		
	Autistic Disorder level 2	42	24,4		
	Autism Disorder (DSM-IV)	29	16,8		

	Asperger's syndrome	40	23,3
	Rett's syndrome	0	0
	Childhood Disintegrative Disorder	1	0,6
	Pervasive developmental disorder not otherwise specified	33	19,2
<b>Gender of the child with ASD</b>	Boy	140	81,4
	Girl	32	18,6

For the study of resilience, the Wagnild and Young (1993) resilience scale was chosen, which has been translated into Greek and consists of 25 statements, in which the respondents are required to indicate their level of agreement or disagreement (from 1 = strongly disagree to 5 = strongly agree). Scores are summed, with higher scores indicating higher resilience of the respondent. According to Neill and Dias (2001), this scale demonstrates concurrent validity, supported by significant correlations between its scores and those of other scales measuring morality, depression and life satisfaction. Regarding reliability, it is high with Cronbach's  $\alpha=0.91$  (Wagnild & Young, 1993). The questionnaire for mothers of children with ASD included additional demographic questions related to their child with the disorder.

The administration of the questionnaires and the collection of the answers took place from April to September 2023. The questionnaire was sent electronically to parent and guardian associations of children on the autism spectrum from all over Greece, as well as to mothers of children with typical development, through parent and guardian associations and schools from various regions of the country, and Facebook pages with mothers. It was distributed to individuals of both genders. There were 325 female respondents and only 12 male respondents, so the research could not be generalized for both sexes. Therefore, men's responses were not included. The message accompanying the questionnaire emphasized that participation was voluntary, responses were anonymous and that they would be used only for research purposes.

Statistical analysis of the data was conducted using IBM SPSS Statistics 28 software. The Cronbach's  $\alpha$  reliability test in this study is 0.94, ensuring the internal consistency of the questions. Before conducting inferential statistical tests, the normality of the response distributions was checked using Kolmogorov-Smirnov test, which indicated normal distributions with values of 0.56,  $df=144$ ,  $p=0.2$  for mothers of children with ASD, and similarly 0.60,  $df=144$ ,  $p=0.2$  for mothers of typically developing children. To compare the mean resilience scores of mothers with children with ASD versus those with typically developing children, a multivariate analysis of variance was applied, considering factors such as maternal category (with or without a child with ASD), maternal age, educational level, and number of children in the family ( $2 \times 2 \times 3 \times 3$ ). Independent samples t-test was used for comparing mean scores between two groups, while one-way analysis of variance (ANOVA) was used for comparisons involving more than two groups. The statistical significance of the differences was tested at a significance level of  $\alpha=5\%$ .

### Results

The main objective of the research is to compare the resilience of mothers of children with ASD and those with typically developing children. The results of the multivariate analysis of variance revealed that the average resilience of mothers with children with ASD differed statistically significantly from that of mothers with typically developing children,  $F(1,289) = 4.15$ ,  $p = 0.042$ . Mothers with children without ASD had a higher average resilience ( $M = 3.93$ ,

SD = 0.45) than mothers who have to take care of a child with an autistic disorder (M = 3.72, SD = 0.49).

The factor maternal age also differentiated the results to a statistically significant degree, with  $F(1,289)=4.11$ ,  $p=0.043$ , where the older mothers scored a higher mean than younger ones (25-40 years old M=3.83, SD=0.48 and 41-61 years old M=3.93, SD=0.48). From the study of the averages of the two age categories of mothers and after applying an independent samples t-test, it was found that this difference only concerned the category of mothers of children with ASD and not those with typically developing children, with  $t(170)=2.55$ ,  $p=0.011$  (25-40 years old M=3.72, SD=0.46 and 41-61 years old M=3.91, SD=0.51).

Another factor that noted statistically significant differences was that of educational level. Mothers of secondary education showed higher resilience scores compared to those with university or postgraduate studies, with  $F(2,289)=3.32$ ,  $p=0.037$  (secondary education graduate M=3.98, SD=0.45, University education M=3.81, SD=0.49, master's/PhD holder M=3.88, SD=0.49). In the case of this factor as well, the statistically significant differences only concerned the category of mothers of children with ASD, as measured by one-way ANOVA, with  $F(2,169)=5.73$ ,  $p=0.004$ . University graduate mothers and those with master's/PhD degree who have a child with autism scored lower resilience (secondary education graduate M=4.03, SD=0.37, University education M=3.74, SD=0.52, master's/PhD holder M=3.76, SD=0.51).

Finally, the factor number of children in the family did not lead to statistically significant differences in either of the two groups of mothers, and similarly, no statistically significant interaction emerged among the studied factors.

### **Conclusions**

From the analysis of the research results, it emerged that mothers of children with ASD are less resilient than mothers of typically developing children. This finding agrees with previous studies (Alrahili, 2023; Craig et al., 2016; Kotera et al., 2021; Malla & Taha, 2022; Smith et al., 2010; Van Bourgondien et al., 2014) and may be due to the fact that mothers of children with ASD often face greater social life limitations, more conflicts within family and social environments, financial difficulties due to increased needs of their child and increased challenges and difficulties in daily life (Alrahili, 2023). Other possible reasons include lack of structures and limited support from the state and the community, lack of free time and denial of acceptance of the situation by themselves or other family members (Santoso, 2022). All of the above burden the lives of these mothers and lead to high levels of anxiety, negative thoughts and feelings, mental and physical fatigue and consequently a decrease in resilience. This current finding disagree with the study by Flores-Buils and Andrés-Roqueta (2022), which reached the opposite conclusion, namely that parents of children with neurodevelopmental disorders, particularly parents of children with ASD, are more resilient compared to parents of typically developing children, as well as with the study by Pastor-Cerezuela et al. (2021) that did not find significant differences in resilience between the two groups of mothers.

Age is a significant differentiating factor among all mothers, regardless of whether their children have ASD or not. However, it plays a larger role among mothers of children with ASD, with older mothers being more resilient. This finding is also confirmed by findings of other similar studies (Buchholz, 2022; Malla & Taha, 2022; Smith et al., 2010), which attribute it to the fact that older individuals exhibit greater emotional stability, have more experience in managing difficult situations and have found ways and strategies to cope with these challenges. However, other research has shown no statistically significant correlation between resilience and parental age (Flores-Buils & Andrés-Roqueta, 2022; Ghanouni & Eves, 2023; Şanlı, 2023; Sinha et al., 2016).

Another statistically significant factor influencing resilience is the educational level of the mothers. Specifically, this difference is significant among mothers of children with ASD, with secondary education graduates being more resilient compared to those with a university or a

master's/PhD degree. This finding aligns with the results of other relevant studies (Buchholz, 2022; Dey & Amponsah, 2020; Koziarz et al., 2021; Şanlı, 2023), which attributed lower resilience levels of degree-holding parents to feelings of shame or to higher expectations for their children's education and progress, which, due to their cognitive limitations, make it almost impossible to meet their parents' expectations. In contrast, Kavalioti's (2017) research conducted on a Greek population reached the opposite conclusion, namely that more educated mothers are also more resilient.

The number of children in the family did not differentiate the mothers' resilience, a finding that agrees with the researches of Alrahili (2023) and Flores-Buils and Andrés-Roqueta (2022). Mothers may experience increased challenges and pressure and feel anxious about the "burden" that their typically developing children might bear having a sibling with ASD. However, other studies link a larger number of children in the family with greater adaptability and control of negative emotions (Greeff & van der Walt, 2010; Smith et al., 2010), which was not found in the present study.

In summary, the findings of the present study, in agreement with the majority of studies, showed that mothers of children with ASD are less resilient compared to mothers of typically developing children. The factors "mother's age" and "educational level" influence the resilience of mothers with children with ASD, with older mothers and less educated mothers being more resilient. The factor "number of children in the family" did not appear to affect either group of mothers. However, the results of our study are in contradiction with the findings of some other similar studies, indicating that further research is necessary to accurately determine the resilience of mothers of children with ASD and to identify the influence that the above factors may have on their resilience when raising a child with ASD.

As the sample in the present study was limited to mothers, it would be beneficial to include a larger sample with corresponding representation of fathers of children with ASD and fathers of typically developing children and also with diagnosis of the same diagnostic and statistical manual. Factors such as the severity of the disorder, the age and the gender of the child with ASD would also be important to include in future research. Additionally, it would be interesting to examine the resilience of siblings of individuals with ASD, as these children have to manage situations and relationships different from those with typically developing siblings. Furthermore, future research could focus on other protective factors of resilience, such as counseling support for parents from health professionals, strong family bonds and good couple communication. Finally, the extension of the research to parents of children with ADHD, intellectual disabilities, learning difficulties and other educational needs would shed more light on the issue of resilience among parents of children with disabilities. Focusing research on the resilience of these parents, who often need psychological support, would greatly contribute to this population group which is vulnerable not only psychologically but also economically and socially.

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