

# STRESS AND RESILIENCE IN PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD): CORRELATION WITH CHARACTERISTICS OF A CHILD WITH ASD<sup>3</sup>

## SUMMARY

*The research was conducted to get insight into the levels of stress and resilience in parents of children with autism spectrum disorder (ASD) and into the correlation with problem behavior, communication, interest in others, and rigid routines in children with ASD. Seventy (70) parents of children with ASD, participated in the research. The research found moderate levels of stress and moderately high levels of resilience in parents. Among the characteristics of a child, problem behavior has the most statistically significant correlation with parental stress and resilience. Problem behavior of children with ASD is more present in families with more general and parental stress and less resilience, more*

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3 Croatian translation of manuscript available at online issue

Received: June, 2022

Accepted: August, 2023

UDK: 159.942-055.52:616.896-053.2

DOI:10.3935/ljsr.v30i3.503

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## Keywords:

parents of children with ASD; stress; resilience; problem behavior; autism spectrum disorder.

*precisely, in families with poor communication, weak coping with problems, and less connection between family members. Communication of a child with ASD is not related to stress and resilience in parents. A child's interest in others is related to stress and family connectedness, while the routines of a child with ASD are associated with some parental resilience factors. Overall, the results suggest that support programs for parents should include activities that rise their awareness of their strengths, and increase family connectedness, communication and constructive problem-solving in order to reduce stress and increase resilience and a child with ASD functioning.*

## INTRODUCTION

According to the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition: DSM-5, autism spectrum disorder (hereinafter ASD) is a complex developmental condition involving persistent challenges with social communication, restricted interests, and repetitive behavior (American Psychiatric Association, 2013.).

On average, parents of children with ASD experience significantly higher levels of stress than parents of children with other developmental difficulties and parents of children with typical development (Pastor-Carezuela et al., 2021.; Estes et al., 2013.; Hayes and Watson, 2012.). Raising a child with ASD is often a positive experience, but it also poses emotional, physical and financial challenges to a family (Higgins, Bailey and Pearce, 2005.). Often, family life revolves around a child with ASD, and such an intense focus on the child's needs often results in chronic stress and neglect of other aspects of family life (Hoogsteen and Woodgate, 2013.).

Research to date has yielded inconsistent results regarding the relationship between the characteristics of a child with ASD and parental stress. While behavioral problems are consistently associated with higher levels of parental stress (Rodriguez, Hartley and Bolt, 2019.; Barroso et al., 2018.; Peters-Scheffer, Didden and Korzilius, 2012.), the relationship between parental stress and the severity of the symptoms of ASD is not entirely clear. Di Renzo et al. (2021.) investigated the relationship between parental stress and the symptoms of ASD in young children and found that the stress of those parents was not caused by the symptoms of ASD. In their sample, over 50 % of children had severe and moderately severe symptoms of ASD. Equally, Peters-Scheffer et al. (2012.) found no relationship between the severity of the symptoms of ASD and parental stress in a sample of 104 mothers of children with ASD and intellectual disabilities aged 2 to 9. However, numerous research has established a relationship between those variables (Rodriguez, Hartley and Bolt, 2019.; Lyons et al., 2010; Siman-Tov and Kaniel, 2011.; Perry, Harris, and Minnes, 2005.), which may be related to differences in methodological characteristics and samples in individual research. Rodriguez, Hartley and Bolt (2019.) measured the symptoms of ASD in a sample of 188 predominantly male children with ASD

aged 5 to 12. It was done using SRS-2, which focused on difficulties in the social functioning of children with ASD. The research found a two-way relationship between parental stress and the symptoms of ASD. Using CARS to determine the severity of symptoms in children with ASD with an average age of 8 years, Lyons et al. (2010) concluded that the severity of the symptoms of ASD is the most consistent predictor of parental stress in all stress domains researched. Further research of correlations between parental stress and characteristics of children with ASD is needed to define possible solutions for support to children with ASD and their families.

The transactional model of child development (Sameroff, 2009.) suggests that parent-child interactions show lasting and reciprocal connections. In other words, the presence of problem behavior contributes to increased levels of parental stress, which inadvertently alters parental behavior in ways that amplify the presence of problem behavior (Hastings, 2003.; Guralnick, 2011.). The described two-way relationship between parental stress and a child's problem behavior has been observed in some research (Rodriguez, Hartley and Bolt, 2019.; Robinson and Neece 2014.). Robinson and Neece (2014.) provided clear evidence of a transactional relationship between parental stress and a children's problem behavior during early and middle childhood with a longitudinal study. Parental stress is both a precursor and a consequence of a child's problem behavior, just as that behavior is both a precursor and a consequence of parental stress. Interestingly, this transactional model in children with developmental disabilities is similar to that in children without disabilities (Robinson and Neece, 2014.). Moreover, studying the relationship between stress in parents of children with ASD, the symptoms of ASD, and internalized and externalized behavioral problems in children with ASD, Rodriguez, Hartley and Bolt (2019.) found that parental stress is a key driver of increasing the symptoms of ASD and internalized and externalized behavioral problems, especially in middle and late childhood. Recently, by focusing on the outcomes of families coping with different sources of stress and processes of adapting to a new situation, authors have increasingly been focusing on identifying and enhancing family strengths, opportunities, and resources for successful adjustment (Seligman and Csikszentmihalyi, 2000.; Fenning and Baker, 2012.), instead of focusing primarily on family sources of dysfunction, as has been the practice in the traditional approach to working with families (Goldenberg and Goldenberg, 2008.).

Therefore, the resilience of both the family as a whole and individual family members can help cope with the stress and challenges associated with raising a child with ASD (Bekhet, Johnson, and Zauszniewski, 2012.). Walsh (2010.) defines resilience as active fighting, practical living, learning from adversity, and integrating experiences into personal and family life. Despite unusual challenges faced by families of children with ASD, most research reports good to moderate levels of resilience in families of children with ASD (Duca, 2015.; Pastor-Cerezuela et al., 2015.). In one of the few studies conducted on stress and resilience in parents of children

with ASD in the Republic of Croatia, Matišić (2021.) found a negative relationship between stress and resilience in families of children with ASD. In other words, the levels of stress were lower if resilience within the family was higher. Regarding the characteristics of a child with ASD, Matišić, (2021.) found that the age of a child with ASD does not have a significant correlation with general stress, parental stress nor resilience in parents of children with ASD. However, the same research found a significant positive correlation between the problem behavior of a child with ASD with general stress and parental stress and a significant negative correlation with resilience in parents of children with ASD.

Recently, there has been more research evaluating programs for parents of children with ASD. Although all interventions seek to help parents of children with ASD establish positive interactions and improve knowledge and skills in overcoming the challenges of problem behavior, there is a great variety of goals to be achieved in working with parents (Lichtle et al., 2020.). Bearss et al. (2015.a, 2015.b) distinguish between programs for parents aimed at increasing knowledge about autism (parental support), while others focus on parents learning specific skills to stimulate changes in a child's behavior (parent-assisted intervention). A systematic review of interventions that sought to reduce the stress levels of parents of children with ASD (Lichtle et al., 2020.) shows that of the eight successful, six are in some way related to increased focused awareness of parents. Research to date has reported a positive impact of the mindfulness program on emotional balance and parental well-being (Benn et al., 2012.). A systematic review and meta-analysis of the effect of the mindfulness program on parental stress and the improvement of the psychological functioning of their children show a possible positive effect, especially on the reduction of externalized problems in children's behavior (Burgdorf, Szabó and Abbott, 2019.).

## **AIM AND PURPOSE OF THIS RESEARCH**

In Croatia, there is a lack of research on the stress and resilience of parents of children with ASD as well as research on the relationship between parental stress/resilience and the characteristics of a child with ASD, especially with problem behavior.

Children with ASD have difficulty communicating, may show difficulty coping with routine changes and new experiences, and may have reduced interest in others. However, we do not know if those symptoms are related to parental stress and resilience. To gain a more accurate understanding, this research provides insight into the levels of stress and resilience in parents of children with ASD, taking into account stress and resilience factors. The correlation between child characteristics (problem behavior of children with ASD, their independence from rigid routines,

and interest in others) and parental management of general stress, factors of parental stress and resilience will also be investigated.

Based on the results of the research, guidelines will be given for future support programs for parents of children with ASD in order to reduce parental stress and increase parental resilience and functioning of children with ASD.

## RESEARCH METHODS

### Research participants

The participants in the research are parents (N = 70) of children with autism spectrum disorder aged 3 to 17 living in Croatia, more precisely from three Dalmatia counties: Split-Dalmatia, Zadar, and Šibenik-Knin counties. One of the parents of a child with ASD participated in the research, and the vast majority of participants (92.9 %) are mothers.

The majority of parents (55.7 %) are aged between 35 and 44. There is the same number of younger parents, aged 25 to 34 (21.4 %), and older parents, aged 45 to 54 (21.4 %), while only 1.2 % of parents are older than 55. At the time of the survey, 81.4 % of parents were married, 11.4 % were divorced, and 4.3 % of participants were in a domestic partnership. There were 1.4 % of single parents, widows, and widowers, which is the smallest share of participants in the sample. Most parents have a four-year or five-year secondary education (30 %), a smaller number of parents have a three-year vocational education (17.1 %), and only two parents have a postgraduate education (2.8 %). Family income, based on parents' perception, is average in most families (87.1 %), five families have below-average income (7.1 %), and four families have above-average income (5.7 %). Most parents were employed at the time of the survey (74.3 %). Parental care rights are used by 31.4 % of parents and leave for caring for a child with disabilities is used by 37.1 % of parents. However, 25.7 % of parents are not employed. The majority of parents (60 %) participated in support programs organized for parents of children with ASD.

The majority of children with PSA (58.6%) are between 7 and 12 years old. There were 25.7% of children under the age of 7, while 15.7% of children with PSA were between the ages of 13 and 17. The largest number of children (58.6%) was diagnosed with an autism spectrum disorder or from the autism spectrum, while the smallest number (5.7%) was diagnosed with Asperger syndrome. Furthermore, 21.4% of children have a diagnosis of pervasive developmental disorder-not otherwise specified (PDD - NOS) and 20% of them have a diagnosis of autism. According to the parents' assessment, 48.6% of children with ASD need full support in their daily functioning, 24.3% need a high level of support, 22.9% moderate, and 4.3% little support.

## Measurement tools

### General Questionnaire on Characteristics of a Child with ASD

For the purposes of this research, a questionnaire was made for parents to describe the characteristics of a child with ASD, i.e., the severity of symptoms, through four areas related to the child's communication, socialization, the need for rigid routines, and frequency of problem behavior. Research participants were offered four to six statements describing the child's behavior in each area. Parents marked those claims that related to their child. The higher the overall score for communication, independence from rigid routines, and the child's social interest, the better the child's functioning. The higher the score on the frequency of problem behavior, the worse the child's functioning.

### MSF-P - Multidimensional Stress Questionnaire for Couples

General stress, i.e., stress caused by external factors, was measured by the Multidimensional Stress Questionnaire for Couples by Bodenmann, Schär and Gmelch (2008.). The questionnaire consists of eight variables: work or education, social contacts, leisure, children, life situations, the immediate and wider environment, income, and daily struggles. The task of the participants was to assess the level of stress for each variable, where 1 is "not stressful at all" and 4 is "very stressful". Questionnaire covers different areas of life, and it cannot be considered a psychometric scale. However, the average score of all eight variables still reflects the individual levels of stress. The overall reliability is  $\alpha = .893$ .

### PSS - Parental Stress Scale

The Parental Stress Scale (PSS) by Berry and Jones (1995.) is an 18-part instrument that assesses parents' feelings about their parenting role, i.e., it measures stress caused by both positive (e.g., emotional benefits, personal development) and negative aspects of parenting (e.g., resource requirements, feelings of stress). Factor analysis singled out four factors: parental rewards, parental stressors, parental lack of control, and parental satisfaction. Research participants indicated a level of agreement or disagreement with a particular statement, 1 meaning "I strongly disagree" and 5 meaning "I strongly agree". The final result of parental stress is obtained by summing all the items together. The possible range of PSS is from 18 (low levels of stress) to 90 (high levels of stress). It is important to note that items 1, 2, 5, 6, 7, 8, 17, and 18 are inverted and recoded in the analysis. The overall reliability is  $\alpha = .907$ , and Table 1 shows the reliability for individual factors.

### FRAS - Family Resilience Assessment Scale

The Family Resilience Assessment Scale (FRAS) by Sixbey (2005.) (Croatian adaptation by Ferić, Maurović and Žižak, 2016.) examines resilience within a family,

i.e., constructs of resilience. The scale consists of 54 items divided into 6 factors by which the research participants indicated the level of agreement or disagreement with the statement, 1 meaning “I strongly disagree” and 4 meaning “I strongly agree”. The factors are Family Communication and Problem Solving, the Ability to Find Meaning in Adversity, Neighbor Support, Family Spirituality, Family Connectedness, and Security and Community Support. The possible range on FRAS is from 54 (low levels of resilience) to 216 (high levels of resilience). Items 33, 37, 45, and 50 are negatively oriented and recoded in the analysis. The overall reliability is  $\alpha = .954$ , and Table 1 shows the reliability for individual factors.

**Table 1.** PSS and FRAS with Corresponding Item Number and Cronbach’s alpha

PSS - Parental Stress Scale		FRAS - Family Resilience Assessment Scale		
Parental rewards (k = 6, $\alpha = .838$ )	Parental stressors (k = 6, $\alpha = .851$ )	Family communication and problem solving (k = 27, $\alpha = .970$ )	Ability to find meaning in adversity (k = 7, $\alpha = .752$ )	Neighbor support (k = 3, $\alpha = .680$ )
Parental lack of control (k = 3, $\alpha = .835$ )	Parental satisfaction (k = 3, $\alpha = .794$ )	Family spirituality (k = 5, $\alpha = .797$ )	Family connectedness (k = 7, $\alpha = .621$ )	Security and community support (k = 5, $\alpha = .893$ )

Table 1 shows that most factors exhibit higher levels of reliability, while internal reliability of Neighbor Support and Family Connectedness factors on FRAS is of medium value. This is probably due to the size of the construct that contains a small number of items and a relatively small sample. Furthermore, the stated values mostly coincide with some research that used adaptations of FRAS (Ferić, Maurović and Žižak, 2016.). Scale reliability data will be taken into account when interpreting the data obtained.

## Data collection and processing

The research was conducted online during January and February 2021. An online questionnaire was created using Google Forms. The link was forwarded to clinics, kindergartens, schools, and associations that work with parents of children with ASD to inform them about the research. The criterion for selecting participants was that they have to be parents of a child with ASD aged 3 to 18 years and live in Split-Dalmatia, Zadar, or Šibenik-Knin counties. The research was conducted in accordance with the Code of Conduct. The purpose of the research was explained to parents of children with ASD before completing the questionnaire and they were

informed about their rights (anonymity and the possibility of withdrawing from the research at any time).

The collected data were analyzed with the statistical package for data processing IBM SPSS, version 24.0. Descriptive statistics and non-parametric statistical methods were used in the framework of scientific research approaches. Before examining the relationship between the child’s characteristics and parental stress and resilience, the Kolmogorov-Smirnov test was performed to examine the normality of the distribution of results. The obtained results showed significant deviations from the normal distribution on all measuring instruments, therefore the Spearman’s correlation coefficient was used to determine the relationship between variables.

## RESULTS AND DISCUSSION

The overview of the results begins with insight in the percentage of representation of certain characteristics of children with ASD in the total sample. The average indicators on the summary variables of individual characteristics of a child with ASD, general and parental stress, resilience, and factors of stress and resilience in parents of children with ASD will be displayed then.

**Table 2.** *Share of certain characteristics of children with ASD in the total sample*

Characteristics of a Child with ASD	Modality	Share in the Total Sample of Children with ASD (%)
Communication	Does not speak	15.7
	Does not speak but uses an assisted communication system	25.7
	Uses only one word	5.7
	Uses phrases of two or three words	22.9
	Uses sentences with four or more words	15.7
	Uses complex sentences	14.3
Independence from rigid routines	Needs routines and is very attached to them	24.3
	Has expressed a need for routines, and they are disruptive	20.0
	Needs routines, and they are not disruptive	40.0
	No need for routine	15.7



Child's socialization and interest in others	Shows no interest in others	10.0	
	Shows interest for certain individuals	65.7	
	Shows interest in others	24.3	
Frequency of problem behavior	Aggression	Never	32.9
		Rarely	30.0
		Sometimes	28.6
		Often	5.7
		Very often	2.9
	Auto-aggression	Never	40.0
		Rarely	27.1
		Sometimes	25.7
		Often	5.7
		Very often	1.4
	Stereotypical behavior	Never	7.1
		Rarely	17.1
		Sometimes	32.9
		Often	27.1
		Very often	14.3
Destructive behavior		Never	38.6
		Rarely	27.1
		Sometimes	20.0
		Often	7.1
		Very often	7.1

By observing the average results on the summary variables of the child's characteristics (Table 3), the results suggest that children with ASD from this sample have average communication, i.e., they mostly speak using phrases of a few words. It is important to note that 25.7 % of children use assisted communication (Table 2). Children with ASD in this sample mostly show interest in others, i.e., for a smaller group of known people. Independence from rigid routines in children with ASD in this sample is moderate; in 55.7 % of children, routines are not disruptive, or a child does not need rigid routines (Table 2). Average scores on the variables of frequency of problem behavior indicate that children with ASD sometimes exhibit problem behavior (Table 3). Among problem behavior, 41.4 % of children with ASD most commonly show stereotypical behavior. Destructive behavior is common in 14.2 % of children with ASD in this sample, aggression in 8.6 % of children, and auto-aggression in 7.1 % of children (Table 2).

**Table 3.** *Basic Statistical Indicators in the Questionnaire on the Characteristics of a Child with ASD and the MSF-P, and Factors on the PSS and the FRAS*

	<b>M</b>	<b>Med</b>	<b>SD</b>	<b>Min</b>	<b>Max</b>
Communication	3.40	4	2.39	1	6
Independence from rigid routines	2.47	3	1.03	1	4
Socialization and interest in others	5.11	6	2.00	1	8
Frequency of problem behavior	2.39	2.25	.81	1	5
Multidimensional Stress Questionnaire for Couples	2.55	2.38	.77	1.38	4.00
Parental Stress Scale	2.27	2.22	.65	1	4.11
Family Resilience Assessment Scale	3.07	2.99	.42	2.13	3.80
Factors on the Parental Stress Scale					
Parental rewards	1.55	1.42	.06	1	3
Parental stressors	2.88	3.00	.91	1	5
Parental lack of control	2.25	2.00	1.09	1	5
Parental satisfaction	2.00	2.00	0.86	1	5
Factors on the Family Resilience Assessment Scale					
Family communication and problem solving	3.25	3.19	.52	2	4
Ability to find meaning in adversity	3.17	3.14	.47	2.14	4
Neighbor support	2.13	2.00	.70	1	4
Family spirituality	2.48	2.40	.71	1.20	4
Family connectedness	3.26	3.28	.47	2.14	4
Security and community support	2.81	3.00	.65	1.20	4

Average values on the Multidimensional Stress Questionnaire for Couples and the Parental Stress Scale indicate that parents of a child with ASD experience moderate levels of stress (Table 3).

Values on parental stress factors, shown in Table 3, suggest that parents of children with ASD in this sample estimate the lowest levels of stress about parental rewards. Parents estimate that they mainly enjoy time with their children, and

achieve closeness, love, and happiness. They also estimate low levels of stress in relation to parental satisfaction and express that they are mainly satisfied with parenthood. Slightly higher, moderate levels of stress are found in the lack of parental control, which means that parents, to a lesser extent, think that they would not decide to have children today and that children are overwhelming and limiting parents' possibilities and control over life. Parents of children with ASD express the highest but still moderate levels of stress in relation to parental stressors, which means that they moderately notice that parental responsibilities do not leave them time and flexibility in life, that it is difficult to balance responsibilities, that caring for a child requires more energy and time than they can provide, and, to some extent, that they carry a financial burden. Unlike previous research that found high levels of stress in parents of children with ASD (Baker-Ericzen, Brookman-Fraze and Stahmer, 2005.; Hayes and Watson, 2012.), this research found moderate levels of general and parental stress in parents of children with ASD from Dalmatia (part of Croatia), which is contributed by parents' awareness of parental rewards and parental satisfaction.

As it is shown in Table 3, the average values on the Family Resilience Assessment Scale suggest that families have moderate to high resilience. Parents of children with ASD express the highest levels of resilience in relation to family connectedness, which means that they listen to each other when they share their worries, feel good when they devote time and energy to family, show each other that they care, show affection and love, and feel like part of the family. High levels of resilience were also expressed in relation to family communication and problem solving. This indicates that they can talk about how they communicate in a family, they are free to express an opinion, they can question what someone actually wanted to say, and they understand the ways other family members communicate. Also, they constructively solve problems in a family, discuss them, and try new ways of solving them.

Slightly lower levels of resilience in regard to previous factors were found in the ability of families of children with ASD to find meaning in adversity, i.e., to accept that problems occur unexpectedly, that stressful situations are a part of life, and that emotional and physical security of family members and respecting family members and friends are prioritized in adversity. Parents of children with ASD express moderately high levels of resilience in relation to safety and community support, which means that they mostly feel safe; they mainly think that people in the community are ready to help them, and they mainly know that they can get community assistance in case of emergency. Compared to other factors, parents of children with ASD express lower levels of resilience in relation to family spirituality and the lowest levels of resilience in relation to neighbor support.

Overall, parents of children with ASD from Dalmatia have a foothold in family connectedness, communication, and constructive approach to problems they face,

which contributes to their moderately high levels of resilience with moderate levels of resilience in relation to accepting adversity, security and community support. Di Renzo et al. (2021.) found that family connectedness is significant in predicting parental stress in mothers of children with ASD, which may be related to the results of this research. Indeed, in the families of children with ASD in this sample, the connection between members is emphasized, contributing to higher levels of resilience and lower levels of stress. The levels of resilience in parents in this sample are higher than those reported by previous research (Al-Jadiri et al., 2021.; Duca, 2015.; Pastor-Cerezuela et al., 2015.; Pastor-Cerezuela et al., 2021.).

Correlation analyses were conducted to investigate the strength and direction of the relationship between the characteristics of a child with ASD, specifically communication, interest in others, and independence from rigid routines, problem behavior, and parental general stress, parental stress, and resilience factors (Table 4).

**Table 4.** Spearman’s Rank Correlation Coefficient Between the Overall Score on the MSF-P, and Factors on the PSS and the FRAS, and the Score on the Variables of Characteristics of a Child

	Frequency of problem behavior	Independence from rigid routines	Socialization / interest in others	Communication
Multidimensional Stress Questionnaire for Couples	.516**	-.227	-.270*	-.059
Parental rewards	.206	-.104	-.185	-.004
Parental stressors	.399**	-.163	-.201	.027
Parental lack of control	.350**	-.232	-.167	.000
Parental satisfaction	.390**	-.132	-.202	.003
Family communication and problem solving	-.274*	.249*	.126	.139
Ability to find meaning in adversity	-.289*	.362**	.146	.120
Neighbor support	.074	-.250*	-.035	-.140
Family spirituality	-.021	-.183	-.044	-.165
Family connectedness	-.252*	.352**	.355**	.187
Security and community support	-.224	.047	.229	-.039

Problem behavior has the most statistically significant associations with parental stress and resilience. The frequency of problem child behavior is correlated (Table 4) with general stress (.516) experienced by parents. This means that levels of stress related to work, social contacts, children, leisure, life situations, family, income, and daily struggles are higher in parents whose children show more problem behavior. In previous research on the same sample of parents of children with ASD, Matišić (2021.) found a significant relationship (.403) between problem behavior and the overall results of parental stress. This research gained more precise insight by finding a significant relationship between problem behavior and the factors of parental stress (Table 4): parental stressors (.399), parental lack of control (.350), and parental satisfaction (.390). Therefore, more frequent stereotypical, destructive, aggressive or auto-aggressive behavior is connected to a higher assessment of parents of children with ASD that parental responsibilities do not leave them time and flexibility in life, that it is difficult to balance responsibilities, that their child is their biggest source of stress, that caring for a child requires more energy and time than they can provide and carries a financial burden. Also, the higher frequency of problem behavior is associated with higher levels of stress in relation to parental lack of control, which means that parents think more about not deciding to have children today, that children are overwhelming and limiting parents' possibilities and control over life. Finally, the higher frequency of problem behavior is associated with higher levels of stress compared to parental satisfaction. The opposite direction should also be taken into account, i.e., parents who have less pronounced parental stress, stress related to lack of control, and stress related to parental satisfaction have children with ASD who show less frequent problem behavior.

The results of this research are in line with the results of previous research that established a relationship between problem behavior of a child with ASD and parental stress (Rodriguez, Hartley and Bolt, 2019.; Peters-Scheffer, Didden and Korzilius, 2012.; Barroso et al., 2018.; Benson 2006.; Davis and Carter, 2008.; Tomanik, Harris, and Hawkins, 2004.).

In previous research that had the same sample, Matišić (2021.) found a high correlation between the frequency of problem behavior and resilience in families of children with ASD. Specifically, families rated their resilience and ability to recover from adversity stronger if the frequency of problem behavior was lower. This research conducted a detailed investigation on the mutual relationship between the factors of family resilience and the presence of problem behavior. The results show that there is a negative correlation between the factors of family communication and problem-solving (-.274), the ability to find meaning in adversity (-.289), and family connectedness (-.252), and the frequency of problem behavior (Table 4). It is interesting that precisely the factors that describe strengths and relationships within families and that contribute most to resilience of families of children with ASD in this research show a significant statistical correlation with problem behavior.

Such a higher frequency of problem behavior is more present in families that have poor communication, that are less constructive in solving problems, that are more difficult to cope with life's adversities, and that are interconnected poorly.

The findings of this research are consistent with Ekas and Whitman (2010.) findings that greater severity of symptoms was associated with poorer psychological well-being and life satisfaction, and a greater prevalence of depression in American mothers. Similarly, a study conducted in Sweden found a negative relationship between maternal well-being and child with ASD behaviors (Allik, Larsson, & Smedje, 2006.). Also, the results of this research support the finding that parental stress harms both parents and their children (Davis and Carter, 2008.; Deater-Deckard, Li and Bell, 2016.). Mothers who are more stressed express more negative than positive feelings, especially when they have poor emotional regulation (Deater-Deckard et al., 2016). Mother's negative emotions and poor emotional regulation negatively affect a child's behavior.

The results of the research indicate the importance of simultaneous action to increase parental resilience and reduce parental stress and problem behavior of children with ASD. One possible strategy is to work on eliminating/mitigating problem behavior through functional analysis of a child's behavior and educating parents to understand the behavior of a child with ASD better, identify their needs and thus prevent the occurrence of problem behavior. By strengthening parents' social and emotional competencies, for example, by improving communication skills, awareness of personal and family strengths, feelings, and behavior, strengthening self-management skills, emotional regulation, and constructive approach to problems, we alleviate parental stress, strengthen parental resilience, and thus increase parental capacity to adequately respond to the needs of a child with ASD and reduce problem behavior.

The connection between interest in others, independence from rigid routines, communication, and stress and resilience factors will be discussed. A child's social awareness or interest in others is negatively correlated with general stress (-.270) and positively correlated with family connectedness (.355). This means that children with ASD show less interest in others in families with more stress related to work, social contacts, children, leisure, life situations, family, income, and daily struggles, and less family connectedness. Children with ASD show greater interest in others in families with less general stress and more interconnectedness, where members listen to each other when they share their worries, feel good when they devote time and energy to family, show each other that they care, show affection and love, and feel like part of the family. The child's interest in the social environment did not appear to be significantly related to parental stress and most resilience factors.

Insistence on equivalence, a tendency to adhere to routine or ritualized patterns, such as eating the same food, difficulty transitioning, and extreme anxiety during small changes (DSM-5, 2013.) is a very present symptom of ASD that can

significantly affect family homeostasis. This research found a statistically significant relationship between a child's independence from rigid routines and four resilience factors. While independence from rigid routines correlates positively with factors of family communication and problem-solving (.249), the ability to find meaning in adversity (.362), and family connectedness (.352), it correlates negatively with neighbor support (-.250). Therefore, children with ASD show greater independence from rigid routines in families with greater interconnectedness, better communication and problem-solving, and a better ability to find meaning in adversity. At the same time, parents of a child with ASD who does not show significant attachment to routines rely less on neighbor support as a potential source of family resilience. This research did not establish a relationship between a child's independence from rigid routines and general and parental stress.

As the results in Table 4 show, a relationship between a child's communication with general and parental stress and parental resilience has also not been established. Given that children with ASD in this sample mostly use speech and an assisted communication system, communication between parents and their children, i.e., children's communication, does not cause stress to parents. In published research (Stanojević et al., 2017.; Tomanik, Harris, and Hawkins, 2004., Baxter, Cummins and Yiolitis 2000.), it is often stated that a child's deviation in expressive and receptive speech and poor communication are a source of stress. The research did not include children with severe communication difficulties, so the findings of this research are not in line with those mentioned above. However, the research by McStay et al. (2014.) confirms the results of this research, suggesting that a child's verbal ability does not affect the perception of parental stress. Regarding a child's communication, Peters-Scheffer, Didden and Korzilius, (2012.) also found that only the initiation of interaction causes stress to parents, while other components of communication did not show significance.

Overall, parents of children with ASD from Dalmatia, mainly mothers who use the internet, mostly generate income through the right to leave to care for a child with disabilities and the right to parental care, and mostly consider their income average, assessed moderate exposure to general and parental stress at the end of the second wave of the COVID-19 pandemic. Parental responsibilities and balancing them and a moderate lack of control over life are the biggest but moderate sources of parental stress. Parents assessed their levels of resilience as moderate to high, and family connectedness, communication, and constructive problem solving were assessed as top resilience factors.

The majority of parents in this sample (60 %) participated in support programs for families of children with ASD. Still, previous research (Matišić, 2021.) did not establish a correlation between support provided and parental stress and resilience. However, a number of positive factors are present in the parents of children with ASD in this sample. The vast majority of parents (85.7 %) are married or in a

domestic relationship, have an average income (87.1 %), are employed (74.3 %), use the right to parental care (31.4 %) and the right to leave to care for a child with disabilities (37.1 %). All of that, according to research to date (Duca, 2015.; Hall and Graff, 2011.; Ekas, Lickenbrock and Whitman, 2010.), possibly contributes to their moderate levels of stress as opposed to high levels of stress in parents in previous research (Baker-Ericzen, Brookman-Fraze and Stahmer, 2005.; Hayes and Watson, 2012.). In addition, a life change caused by the COVID-19 pandemic may have influenced parents to focus on positive relationships within the family and achieving closeness and togetherness, which stands out as the top resilience factor in this research. The impact of family characteristics on stress and resilience in parents of children with ASD in this sample needs to be further investigated and presented in future work.

The relationship between stress and the characteristics of children with ASD observed indicates that problem behavior is associated with general and parental stress, that interest in others is significantly associated with general stress but not with parental stress, and that routines and communication are not associated with general and parental stress. Resilience in parents of children with ASD is associated with problem behavior, so children with ASD show more of such behavior in families with less communication and problem-solving, a poor ability to find meaning in adversity, and poor family connectedness. Interest in others and independence from rigid routines of a child with ASD are associated with parental resilience that stems from family connectedness, so children with ASD function better in families where members listen, respect, and care for each other. In addition, children with ASD show greater independence from rigid routines in families where higher levels of resilience are associated with finding meaning in adversity. Higher levels of resilience based on neighbor support are associated with a greater presence of rigid routines. A possible explanation should be sought taking into account the various factors of parental stress, which combined may leave parents with less strength to cope with challenges arising from the severity of the symptoms of ASD.

Based on the results, it could be suggested that future programs for parents of children with ASD put more attention on balancing of parental responsibilities and raising awareness of their control over their lives in order to reduce their stress. Increasing family connectedness, communication, constructive problem-solving, acceptance of stressful situations in life and respect for family members and friends can be expected to strengthen their resilience. These aspects of the program with parents could contribute to the better functioning of the child with ASD, and the reduction of behavioral problems.



## RESEARCH LIMITATIONS

The results obtained should be taken with caution for several reasons. The results were obtained during the COVID-19 pandemic on a small sample of predominantly mothers who use the internet. The research was conducted at the end of the second wave of the pandemic in Croatia in conditions of partially remote school learning, which is especially challenging for children with ASD (Stenhoff, Pennington and Tapp 2020.). Many parents worked from home, and gatherings and socializing (in associations) were kept at a minimum. The possible impact of the COVID-19 pandemic on parental stress and resilience (due to impact on work, income, lifestyle changes, mental health, etc.) was not considered in this research, which represents a weakness. Due to the pandemic, the research was only possible to conduct online; only participants were parents equipped with a smartphone, tablet, or computer and an internet connection. Parents of children with ASD of poor financial condition and computer literacy could not participate in this way. Consequently, the representation of the sample was limited. The questionnaire contained questions of assessment and self-assessment, so it is possible that the research participants provided socially desirable answers.

## CONCLUSION

The research provides insight into the levels of stress and resilience in parents of children with ASD and the relationship between the characteristics of children with ASD and parental stress and resilience. Parents of children with ASD rated their levels of general and parental stress as moderate and their levels of resilience as moderate to high. Their greatest stress is balancing family responsibilities that take them a lot of time and energy. Their greatest resilience is in closeness, mutual support, communication among family members, and a constructive approach to challenges. The research found a significant relationship between problem behavior and general and parental stress. Therefore, stereotypical, destructive, aggressive, and auto-aggressive child behavior is more present in families with higher levels of general and parental stress, i.e., stress related to balancing parental responsibilities, stress related to lack of control, and stress related to parental satisfaction. Problem behavior is also associated with parental resilience, family communication, constructive problem-solving, finding meaning in adversity, and family connectedness. Such behavior is more prevalent in families with lower levels of resilience, poor communication, coping with problems, and connection among family members. Communication of a child with ASD is not related to parental stress and resilience. A child's interest in others is related to stress, while a child's routines are related to only some parental resilience factors. Interest in others in children with ASD is

higher in families with less general stress and greater interconnectedness. There is greater independence from rigid routines in families with greater interconnectedness, better communication, problem-solving, and a better ability to find meaning in adversity.

The results show that family processes are related to the characteristics of a child with ASD, which emphasizes the importance of strengthening the personal development of parents of children with ASD. This includes raising awareness of their strengths and weaknesses, behavior, emotions, and improving communication and other skills important for achieving family togetherness and satisfaction.

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## **STRES I OTPORNOST RODITELJA DJECE S POREMEĆAJEM IZ SPEKTRA AUTIZMA (PSA): KORELACIJA S OBILJEŽJIMA DJETETA S PSA**

### **SAŽETAK**

Istraživanje je provedeno s ciljem uvida u razine stresa i otpornosti roditelja djece s poremećajem iz spektra autizma (PSA) te njihove korelacije s nepoželjnim ponašanjima, komunikacijom, interesom za druge i rigidnim rutinama kod djece s PSA. U istraživanju je sudjelovalo 70 roditelja djece s PSA. Utvrđena je umjerena razina stresa i umjereno visoka razina otpornosti roditelja. Među ispitivanim obilježjima djeteta, nepoželjna ponašanja pokazuju najznačajniju statističku povezanost s roditeljskim stresom i otpornošću. Nepoželjna ponašanja više su prisutna u obiteljima gdje je veći opći i roditeljski stres, a slabija otpornost, preciznije, u obiteljima sa siromašnijom komunikacijom, otežanim nošenjem s problemima, te sa slabijom povezanosti među članovima obitelji. Komunikacija djeteta s PSA ne korelira sa stresom i otpornošću roditelja. Interes djeteta za druge u korelaciji je sa stresom i obiteljskom povezanošću, dok su rutine djeteta s PSA u korelaciji s nekim faktorima otpornosti roditelja. Rezultati ukupno sugeriraju da bi programi podrške roditeljima trebali uključivati aktivnosti kojima se jača svijest o vlastitim snagama, povećava povezanost unutar obitelji, obogaćuje komunikacija i konstruktivno rješavanje problema, a sve to u svrhu, kako smanjenja stresa unutar obitelji, tako i povećanja otpornosti obitelji i funkcioniranja djeteta s PSA.

**Ključne riječi:** roditelji djece s PSA; stres; otpornost; nepoželjna ponašanja; poremećaj iz spektra autizma.



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