



# STRESS LEVEL AND THE USE OF COPING STRATEGIES OF PARENTS OF AUTISTIC CHILDREN.

NIVEL DE ESTRÉS Y EL USO DE ESTRATEGIAS DE AFRONTAMIENTO DE PADRES DE NIÑOS AUTISTAS.

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## ABSTRACT

**Introduction:** Autism spectrum disorder is a neurodevelopmental disorder that as a consequence has high physical, psychic and economic demand from parents. **Objective:** To determine the association between the level of stress and the use of coping strategies of parents of autistic children of the ARIE Villa El Salvador institute.

**Methods:** Quantitative observational analytical study. Two surveys were used: the Parental Stress Questionnaire, modified Spanish version CEP (PSI-SF) and the abbreviated Multidimensional Coping Styles Assessment Scale Questionnaire. **Results:** A total of 103 parents were surveyed. The level of medium-high stress was 93.14%. Of the coping strategies; strategy A the strategy with the highest mean was planning (10.81 points), of strategy B the strategy with the highest mean was positive reinterpretation and growth (11.22 points), and of strategy C the strategy with the highest mean was mental disconnection (7.53 points). A positive correlation (0.86) was found between the level of stress and the coping test. In the multiple regression it was observed that the level of stress increases 0.81 points (95%CI: 0.718-0.909;  $p < 0.001$ ) for each point that the coping test increases. Furthermore, we found a strength of association between the two of 0.7402.

**Conclusions:** there is an association between stress level and stress coping in parents. The strategies with the highest scores were planning, positive reinterpretation and growth, and mental disconnection.

**Keywords:** Autistic spectrum disorder; Psychologic adaptation; Child. (Source: MESH-NLM)

## RESUMEN

**Introducción:** El trastorno del espectro autista es un trastorno del neurodesarrollo que como consecuencia tiene la alta demanda física, psíquica y económica por parte de los padres. **Objetivo:** Determinar la asociación entre el nivel de estrés y el uso de estrategias de afrontamiento de padres de niños autistas del instituto ARIE Villa El Salvador. **Métodos:** Estudio analítico cuantitativo observacional. Se utilizaron dos encuestas Cuestionario de estrés parental, versión española modificada CEP(PSI-SF) y Cuestionario abreviado de la Escala Multidimensional de Evaluación de los Estilos de Afrontamiento. **Resultados:** Se trabajó un total de 103 padres de familia. El nivel de estrés medio-alto fue 93,14%. De las estrategias de afrontamiento; la estrategia A la estrategia que tuvo mayor media fue la planificación (10.81 puntos), de la estrategia B la estrategia que tuvo mayor media fue la reinterpretación positiva y crecimiento (11.22 puntos), y de la estrategia C la estrategia que tuvo mayor media fue la desconexión mental (7.53 puntos). Se encontró una correlación positiva (0.86) entre el nivel de estrés y el Test de afrontamiento. En la regresión múltiple se observó que el nivel de estrés, aumenta 0.81 puntos (IC95%: 0.718-0.909;  $p < 0,001$ ) por cada punto que incrementa el test de afrontamiento. Además, se encontró una fuerza de asociación entre ambos de 0.7402. **Conclusiones:** existe asociación entre el nivel de estrés y el afrontamiento de este por los padres. Las estrategias con mayor puntuación fueron la planificación, la reinterpretación positiva y crecimiento, y la desconexión mental.

**Palabras clave:** Trastorno del espectro autista; Adaptación psicológica; Niños. (Fuente: DeCS- BIREME)

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## INTRODUCTION

Autism Spectrum Disorder (ASD) is currently understood as a neurodevelopmental disorder reflected in difficulties in communication and social interaction, demonstrated by repetitive and restricted patterns of behavior, activities, and interests. ASD includes autistic disorder (common autism), pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Asperger's disorder or Asperger's syndrome<sup>(1)</sup>.

In the United States, an epidemiological study conducted by the Centers for Disease Control and Prevention showed an increase in the prevalence of childhood autism from 1 in every 500 to 1,000 children, with the predominant age being 0 to 3 years<sup>(2)</sup>. In Peru, 15,700 individuals have ASD, of which 91% are under 11 years old<sup>(3)</sup>. Among its consequences is the high physical, psychological, and economic demand on parents. Additionally, the level of stress is usually high due to the requirements that children with ASD need, leading parents to develop adaptive coping strategies to manage social and family aspects<sup>(4)</sup>.

These coping strategies involve cognitive and behavioral processes that are constantly changing and developed to handle specific external and/or internal demands perceived as excessive or overwhelming<sup>(5)</sup>. For the reasons mentioned above, the objective of this study was to determine the association between the level of stress and the use of coping strategies by parents of autistic children with different degrees of dependency at the instituto ARIE in Villa El Salvador.

## METHODS

### Study design

This is an observational, quantitative, cross-sectional study conducted on a population of parents of patients with autism attended at the Instituto para el desarrollo infantil ARIE in Lima, Peru. The study included the father or mother of children with autism who are treated at the Instituto para el desarrollo infantil ARIE, who are adults, willing to participate in the survey, and who completed the informed consent form. All incomplete or improperly filled surveys and parents who were not caring for a child with autism were excluded. A sample of 103 parents with children with ASD was evaluated.

### Variables

The dependent variable was the coping strategies measured using the Brief COPE Inventory, a Multidimensional Coping Styles Assessment Scale Questionnaire. The main independent variable was the level of parental stress measured using the modified Spanish version of the Parental Stress Index (PSI-SF). Other variables included age, gender, number of children, and the presence of additional caregivers.

### Procedures

With prior permission and knowledge of the parents, the researchers conducted surveys with the parents, and this information was transcribed into an Excel sheet without any identifying data; only variables important for the study were included.

### Statistical analysis

Statistical analysis was performed using STATA v16.0 software. For descriptive analysis, qualitative variables were summarized in percentages, while quantitative variables were presented as mean and standard deviation. In the bivariate analysis, the T-Student test, ANOVA, and Pearson's test were used.

A generalized linear multivariate model of the Gaussian family was performed based on a linear regression model. The variables included in the multivariate model were age, gender, number of children, and the presence of additional caregivers. These variables were chosen based on a literature review. The measure of association was the prevalence ratio (PR) with a 95% confidence interval (CI). The strength of the association between the main variable and the two predictive formulas with the highest correlation was measured using the R-squared.

### Ethical aspects

This study followed the guidelines of the Declaration of Helsinki, maintaining the anonymity of any data that could reveal the identity of the patient's family member; therefore, the medical record number was used for identification in the data. This project was evaluated by the ethics committee of the Universidad Ricardo Palma for review, correction, and execution. All participants signed the informed consent form.

## RESULTS

A total of 103 parents were included in the study. The median age was 39 years; there was a predominance of females (70.59%), the majority had 2 or more children (59.80%), and only 21.57% had additional caregivers.

The medium level of stress was 88.24%, and the high level was 4.9%. The mean stress level was 95, and the mean COPE test score was 129.59 (Table 1).

**Table 1.** Sociodemographic characteristics of the sample of parents.

Characteristics	n (%)
<b>Age</b>	39 (9.41)*
<b>Sex</b>	
Male	30 (29.41)
Female	73 (70.59)
<b>Number of children</b>	
< 2	41 (40.20)
> o = 2	62 (59.80)
<b>Has additional caregivers</b>	
No	80 (78.43)
Yes	23 (21.57)
<b>Categorized stress level</b>	
Low	8 (6.86)
Medium	90 (88.24)
High	5 (4.90)
<b>Stress level</b>	95 (28.30)*
<b>COPE test</b>	129.59 (26.44)*

\*Mean (standard deviation)  
Source: Own elaboration

The means of the COPE strategies are described. In Strategy A, the strategy with the highest mean was planning<sup>(10,91)</sup>. In Strategy B, the strategy with the

highest mean was positive reinterpretation and growth<sup>(11,22)</sup>. In Strategy C, the strategy with the highest mean was mental disengagement<sup>(7,53)</sup>. (Table 2)

**Table 2.** COPE Test strategies in a sample of parents.

Strategies	Mean (standard deviation)
<b>Strategy A</b>	
Planning	10.81 (2.64)
Active coping	9.67 (2.04)
Suppression of competing activities	9.63 (2.31)
Restraint	8.71 (4.41)
<b>Strategy B</b>	
Positive reinterpretation and growth	11.22 (2.27)
Turning to religion	10.83 (8.33)
Use of instrumental social support	10.68 (2,56)
Acceptance	10.16 (2,44)
Use of emotional social support	9.65 (3,02)
Focus and venting of emotions	8.36 (2.39)
Humor	7 (2.78)
Denial	6.44 (2,29)
<b>Strategy C</b>	
Mental disengagement	5 (4.90)
Behavioral disengagement	7.53 (2.12)
Substance use	6.74 (2.18)
Substance use	4.63 (2.51)

Source: Own elaboration

It was observed that those who had a planning strategy had a mean stress level of 8.8; those who had a positive reinterpretation and growth strategy had a mean stress

level of 10.2; and those who had a mental disengagement strategy had a mean stress level of 6.4. No statistically significant association was found (Table 3).

**Table 3.** Bivariate analysis between strategies and stress level in a sample of parents.

Strategies	Stress level			P
	Low	Medium	High	
Planning	13.28 (2.058)	10.73 (2.59)	8.8 (2.39)	0.774*
Positive reinterpretation and growth	13.57 (1.81)	11.1 (2.23)	10.2 (1.30)	0.387*
Mental disengagement	6.28 (1.79)	7.68 (2.13)	6.4 (1.51)	0.629*

\* Performed with ANOVA test, significance level  $p < 0.05$   
Source: Own elaboration

It was observed that those with a high stress level had a higher mean COPE test score of 85.23 points compared to those with a low stress level. Parents with a medium stress level had a higher mean COPE test score of 53.10

points compared to those with a low stress level. With the exception of sex, number of children, and having additional caregivers, the rest of the results presented statistically significant associations (Table 4).

**Table 4.** Bivariate analysis between sociodemographic characteristics and COPE test in a sample of parents.

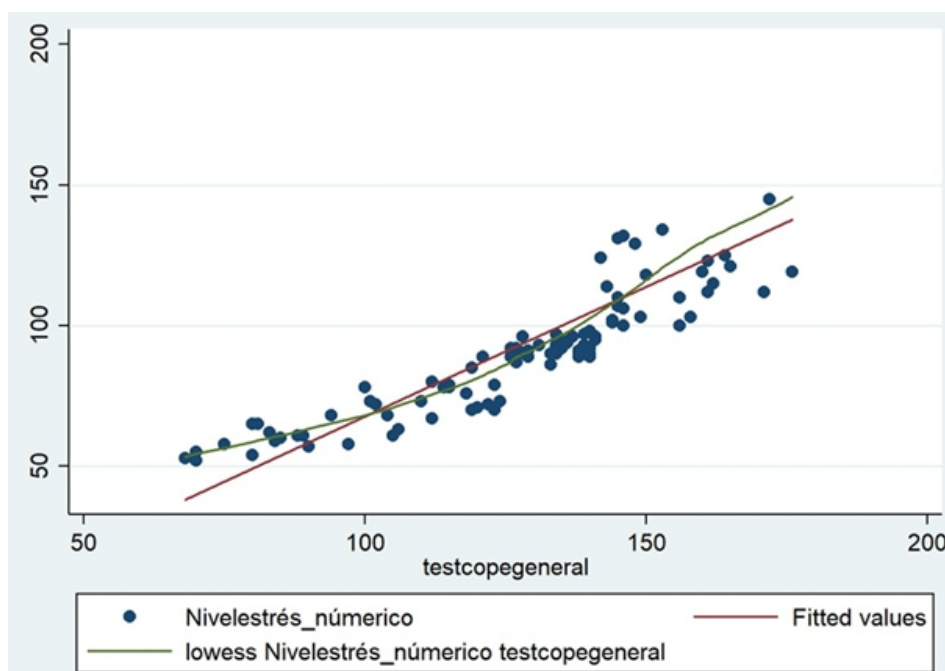
Characteristics	COPE Test	p
<b>Sex</b>		0.1986**
Male	124.367 (4.35)*	
Female	131.77 (3.22)*	
<b>Number of children</b>		0.7136**
< 2	128.46 (3.64)*	
> o = 2	130.36 (3.65)*	
<b>Has additional caregivers</b>		0.0886**
No	127.44 (3.03)*	
Yes	137.45 (4.87)*	
<b>Categorized stress level</b>		<b>0.023***</b>
Low	78.57 (11.13)	
Medium	131.67 (22.52)	
High	163.8 (8.35)	

\* Mean (standard deviation)  
 \*\* Performed with T-test, significance level  $p < 0.05$   
 \*\*\* Performed with ANOVA test, significance level  $p < 0.05$   
 Source: Own elaboration

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There is a positive correlation between stress level and the COPE Test in a sample of parents. In Figure 1, we see the linearity of the stress level values (green line)

and the COPE Test values (red line), as well as the blue scatter points.



**Figure 1.** Correlation between stress level and COPE Test.



The correlation was statistically significant between the stress level and the COPE Test.

The stress level had a strong positive monotonic correlation of 0.86 (Table 5).

**Table 5.** Pearson Correlation Coefficient between Stress Level and COPE Test in a Sample of Parents.

Survey	COPE Test	p
Stress level	0.8604	<0.001*

\* Significance level  $p < 0.05$   
 Source: Own elaboration

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For the first analysis, in the simple regression, it was found that, among parents, the average stress level increases by 0.80 (95% CI: 0.710-0.896;  $p < 0.001$ ) for each point increase in the COPE Test. In the multiple regression, the observed association in terms of direction and magnitude was maintained. It was observed that the average stress level increases by

0.81 (95% CI: 0.718-0.909;  $p < 0.001$ ) for each point increase in the COPE Test. This was adjusted for the confounding covariates of age, sex, number of children, and having additional caregivers. Additionally, the strength of the association between stress level and the COPE Test was 0.7402 (Table 6).

**Table 6.** Crude and adjusted linear regression model comparing stress level and COPE test.

Characteristics	Crude analysis				Adjusted analysis*		
	Coef $\beta$	95 % CI	$p^{**}$	R2	Coef $\beta$	95 % CI	$p^{**}$
Stress level	0.803	0.710-0.896	<0.001	0.7402	0.814	0.718-0.909	<0.001

\* Adjusted for age, sex, number of children, and having additional caregivers.  
 \*\* Significant p-value  $< 0.05$   
 Source: Own elaboration

## DISCUSSION

Our results show that a high level of parental stress was associated with coping with stress as measured by the COPE Test. It was also found that the level of parental stress was significantly and strongly positively correlated with coping with stress. Additionally, the most used strategies were planning, positive reinterpretation and growth, and mental disengagement.

In our study, it was found that the stress level of parents with children with Autism Spectrum Disorder (ASD) was medium-high (93.24%). This was similar to a study conducted on women using social services, where high levels of stress were found<sup>(6)</sup>. Another study conducted on English parents found high levels of stress related to their parenting<sup>(7,8)</sup>. Another study of parents with children with ASD found that 87% of parents experienced stress<sup>(9)</sup>. In our study, using the

PSI/SF questionnaire, the stress level of parents had a mean of 95; this was similar to another study that found scores of 90 using the PSI/SF<sup>(10)</sup>. It has been observed that parents with children with ASD experience significant stress and depression, even more than parents with children with intellectual disabilities and cerebral palsy<sup>(11,12,13)</sup>. Regarding gender, mothers experience more stress in raising a child with ASD compared to fathers<sup>(11)</sup> and compared to mothers with children with facial paralysis<sup>(14)</sup>. In our study, no gender differences were found. Possible explanations for why parents with children with ASD tend to have higher stress levels could be the children's behavioral problems and emotional deficiencies, the lack of respite caregivers, several children with ASD in the household, social support, frustration with the child's improvement, or satisfaction with life, and the instability typical of children with ASD<sup>(14,15,16,17)</sup>.





Because parents with children with ASD experience significant stress, they attempt to manage stress with various coping methods<sup>(18)</sup>. In our study, a strong positive correlation was found between the level of parental stress and coping strategies. A systematic review found that parents' stress levels had a significant positive correlation with positive reappraisal coping<sup>(19)</sup>. Two studies found that parents with children with ASD used maladaptive coping strategies to deal with stress<sup>(12,20)</sup>; it has been seen that having maladaptive coping is associated with higher stress levels<sup>(21)</sup>.

Another study conducted on French parents found that they focused more on problem-focused coping methods than emotion-focused methods and sought social assistance and/or other caregivers<sup>(22)</sup>. In our study, no association was found between parents who had other caregivers and coping strategies. Another study found that parents with a higher burden related to their child's care had increased stress<sup>(23)</sup>. Despite using various coping types, parents continue to experience high stress levels. One possible explanation for this could be that parental stress correlates with negative reappraisal coping, which leads to inadequate knowledge of coping strategies<sup>(12)</sup>; additionally, parents use strategies based on their skills, and it has been seen that parents can manage externalizing behaviors but do not have the tools to manage internalizing behaviors<sup>(20)</sup>.

Thus, the child's behavior can lead to exhaustion, resulting in inadequate coping strategies and consequently increased stress. Various coping strategies such as meditation, sports, good nutrition, relaxation, humor, and leisure activities can help reduce the consequences of stress<sup>(24)</sup>. However, coping strategies for dealing with stress differ according to personality, emotional stance, and the individual's interpretation of the situation<sup>(25)</sup>. In our study, the strategies with the highest scores were planning, positive reinterpretation and growth, and mental disengagement. This was similar to other studies where it was found that the main coping strategies used by parents with children with ASD were planning,

acceptance, positive reinterpretation and growth, and problem-focused coping strategies<sup>(18,22,26)</sup>. Coping strategies such as mental disengagement, active avoidance, and escape avoidance (maladaptive/inadequate strategies) can occur due to crises in homes with children with ASD<sup>(12,20)</sup>; this is related to a lack of knowledge about coping strategies. A possible explanation could be the fatigue of parents related to insufficient coping techniques<sup>(20)</sup>; it has also been observed that parents prefer mental disengagement due to high levels of stress, depression, and negative moods<sup>(23)</sup>.

Various coping strategies were studied by Cohen, which are based on rational thinking, explaining the positive reinterpretation of stressful situations logically; individual imagination, which would be future planning and the consequences of the current situation<sup>(27)</sup>. Other strategies are pointed out by Higgins and Endler, which relate to orientations that include emotions, avoidance, and the best immediate plan to address the stressful situation<sup>(28)</sup>. Kim and Han mention that increased emotional control and efficiency help adapt and practice effective strategies for coping with stress<sup>(29)</sup>. However, variations in how coping mechanisms are employed by parents with children with ASD make it difficult to highlight only one of them, so it could be indicated that coping strategy should be personalized according to the parents' skills and the child's degree of autism.

Our study has limitations. First, the degree of autism in children was not considered. Second, other psychological problems in parents, such as depression and anxiety, were not evaluated. Third, the educational level and economic level of the parents were not considered. However, these findings could be useful for understanding the panorama of stress coping in Peruvian parents with children with ASD. It is concluded that there is a correlation between stress level and coping with stress in parents with children with ASD. Furthermore, its relationship with stress coping strategies was identified; the strategies that scored highest in the studied population were





planning, positive reinterpretation and growth, and mental disengagement.

In the future, studies should investigate the incidence of stress in deciding stress coping strategies and thus understand this behavior in parents with children with ASD. Therefore, children can have better improvement

and understanding from parents; additionally, the quality of life in families with children with ASD would be higher and more positive. The implementation of educational seminar programs and campaigns on this topic for parents with children with ASD should be promoted, providing them with tools for stress coping strategies.

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