THE EMOTIONAL HEALTH OF PARENTS OF CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER: OVERLOAD AND COPING

SAÚDE EMOCIONAL DE PAIS DE CRIANÇAS DIAGNOSTICADAS COM TRANSTORNO DO ESPECTRO AUTISTA: SOBRECARGA E ENFRENTAMENTO

SALUD EMOCIONAL DE PADRES DE NIÑOS DIAGNOSTICADOS CON TRASTORNO DEL ESPECTRO AUTISTA: SOBRECARGA Y AFRONTAMIENTO

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ABSTRACT: The emotional health of parents of children with a disability has been widely discussed in the scientific field, considering that in the exercise of parenthood, the genitors are informal caregivers when taking action in the children's routine with special needs. Even without education in the health field, they perform hygiene care, feed, locomotion, administer medications, form a link with the formal health team, and offer emotional support to the cared person. In the care of children diagnosed with Autism Spectrum Disorder (ASD), the adversities are related to the different clinical presentations of this neurodevelopmental disorder, development markers generally perceived in the first four years of life. In addition to the children's difficulties, the caregivers can face personal challenges with stress, reduction in quality of life, anxiety, and depression. The objective of this research was to investigate the coping strategies, the classification of overload, and the prevalence of anxiety, depression, and stress noticed in parents of children diagnosed with ASD. We conducted a cross-sectional survey with a convenience sample of 50 participants, primary caregivers of children who are up to 11 years old and 11 months old with the diagnosis of ASD. The instruments used were: Sociodemographic Questionnaire, Cognitive Anxiety Scale, Baptista Depression Scale – Adult Version, Perceived Stress Scale, Coping Strategies Inventory, and Zarit Overload Inventory. The results point to strong and positive correlations between the variables of anxiety and depression, as well as between overload and depression. Regarding the relationship between the intolerance factor, vulnerability to cognitive anxiety, and depression, a negative correlation was also observed. The most used coping strategies were acceptance of responsibility and positive reappraisal. We concluded there was a high prevalence of a moderate to severe overload among participants, especially among mothers, and that the coping strategies used may have been functional for the stability of emotional health, specifically for the variables of stress and depression.

KEYWORDS: Emotional adjustment. Caregivers. Coping. Autism. Overload.

RESUMO: *A saúde emocional de pais de crianças com deficiência tem sido discutida no campo científico, considerando que no exercício da parentalidade os genitores passam a ser cuidadores informais ao atuar na rotina dos filhos com necessidade de cuidados especializados. Sem formação na área da saúde, realizam os cuidados de higiene, alimentação, locomoção, administram medicações, formam o elo com a equipe formal de saúde e oferecem suporte emocional para a pessoa cuidada. Nos cuidados da criança diagnosticada com o Transtorno do Espectro Autista (TEA), as adversidades se relacionam as diferentes apresentações clínicas deste transtorno do neurodesenvolvimento, caracterizado por atrasos em variados marcadores do desenvolvimento geralmente percebidos nos primeiros quatro anos de vida. Para além das dificuldades dos filhos, os responsáveis podem enfrentar desafios pessoais como estresse, redução da qualidade de vida, ansiedade e depressão. O objetivo desta pesquisa foi investigar as estratégias de enfrentamento, a classificação de sobrecarga e a prevalência de ansiedade, depressão e estresse percebido em pais de crianças diagnosticadas com TEA. Foi realizado um survey transversal com amostra por conveniência com 50 participantes, cuidadores primários de crianças com idade até 11 anos e 11 meses com o diagnóstico de TEA. Os instrumentos utilizados foram: Questionário Sociodemográfico, Escala Cognitiva de Ansiedade, Escala Baptista de Depressão – Versão Adulto, Escala de Estresse Percebido, Inventário de Estratégias de Coping e Inventário de Sobrecarga de Zarit. Os resultados apontam para correlações fortes e positivas entre as variáveis de ansiedade e depressão, bem como entre sobrecarga e depressão. No que tange à relação entre o fator de intolerância a vulnerabilidade de ansiedade cognitiva e depressão também se observou, correlação negativa. As estratégias de enfrentamento mais utilizadas foram as de aceitação de responsabilidade e reavaliação positiva. Concluiu-se que houve prevalência de sobrecarga moderada à severa entre os participantes, principalmente entre as mães, e que as estratégias de enfrentamento utilizadas podem ter sido funcionais para a estabilidade da saúde emocional, especificamente para as variáveis de estresse e depressão.*

PALAVRAS-CHAVE: *Ajustamento emocional. Cuidadores. Coping. Autismo. Sobrecarga.*

***RESUMEN**: La salud emocional de los padres de niños con discapacidad ha sido discutida en el ámbito científico, considerando que en el ejercicio de la paternidad, los padres se convierten en cuidadores informales al actuar en la rutina de sus hijos necesitados de cuidados especializados. Sin formación en el área de salud, realizan cuidados de higiene, alimentación y movilidad, administran medicamentos, forman vínculo con el equipo formal de salud y ofrecen apoyo emocional a la persona atendida. En la atención a niños diagnosticados con Trastorno del Espectro Autista (TEA), las adversidades están relacionadas con las diferentes presentaciones clínicas de este trastorno del neurodesarrollo, caracterizado por retrasos en diversos marcadores del desarrollo que generalmente se notan en los primeros cuatro años de vida. Además de las dificultades de los niños, los responsables pueden enfrentar desafíos personales como estrés, reducción de la calidad de vida, ansiedad y depresión. El objetivo de esta investigación fue investigar las estrategias de afrontamiento, la clasificación de la sobrecarga y la prevalencia de ansiedad, depresión y estrés percibido en padres de niños diagnosticados con TEA. Se realizó una encuesta transversal con una muestra por conveniencia con 50 participantes, cuidadores principales de niños de hasta 11 años y 11 meses diagnosticados con TEA. Los instrumentos utilizados fueron: Cuestionario Sociodemográfico, Escala de Ansiedad Cognitiva, Escala de Depresión Baptista – Versión Adulto, Escala de Estrés Percibido, Inventario de Estrategias de Afrontamiento e Inventario de Sobrecarga de Zarit. Los resultados apuntan a correlaciones fuertes y positivas entre las variables de ansiedad y depresión, así como entre sobrecarga y depresión. En cuanto a la relación entre el factor intolerancia, la vulnerabilidad a la ansiedad cognitiva y la depresión, también se observó una correlación negativa. Las estrategias de afrontamiento más utilizadas aceptación de la responsabilidad y la reevaluación positiva. Se concluyó que hubo prevalencia de sobrecarga moderada a severa entre los participantes, especialmente entre las madres, y que las estrategias de afrontamiento utilizadas pudieron haber sido funcionales para la estabilidad de la salud emocional, específicamente para las variables estrés y depresión.*

***PALABRAS CLAVE**: Ajuste emocional. Cuidadores. Afrontamiento. Autismo. Sobrecarga.*

Introduction

ASD is classified as a neurodevelopmental disorder characterized by developmental delays, usually noticed in the first four years of the child's life, involving functional impairments in the personal, social, and academic spheres. Specifically, there are *deficits* in communication, personal interaction, and the presence of restricted and repetitive patterns of behavior, interests, or activities, according to the *American Psychiatric Association* (APA, 2023).

In a survey carried out by *the Centers for Disease Control and Prevention* (CDC), Maenner *et al.* (2023) point out that, in 2020, one in every 36 American children aged eight met the diagnostic criteria for ASD. This data highlights the high prevalence of this neurodevelopmental condition, which makes it possible to emphasize that many caregivers may be involved in assisting children.

Gaiato *et al.* (2022), in a study with parents of children with ASD, show that the specifics of the diagnosis, the type of treatment, and the parent's knowledge of the condition can influence the way they deal with the challenges from diagnosis to follow-up interventions.

The authors point out that difficulties related to accepting the diagnosis can also have a significant impact when associated with a lack of information and little access to specialized professionals for care, guidance, and support, considering the psychological repercussions and the impact of the diagnosis on the family.

In a survey of parents of children with and without ASD, during the COVID-19 pandemic, Silva *et al.* (2021) measured that the clinical group (parents of children with ASD) had higher levels of anxiety, depression, and stress. Higher levels of signs of psychopathology were also associated with lower income, being single, having no perceived support network, and higher levels of stress for those who accompanied their children on more than three daily activities. Despite the critical findings in parents of children with ASD, the authors state that the non-clinical group also showed high levels of anxiety, depression, and stress, which highlights the vulnerability of the emotional health of parents of children in general, possibly due to the extensive care routine.

The COVID-19 pandemic may be related to the negative aspects of the emotional health of parents of children with ASD, due to the damage that social isolation has brought to children. Gaiato, Silveira, and Zotesso (2022) discussed that behavioral changes are related to the abrupt change in routine due to the pause in therapeutic interventions, which has generated deregulations in many children, showing a regression in behavioral development. These factors may be related to the parents' overload during the childcare routine, specifically during the period when they were without the necessary interventions.

In a recent study, Vilanova *et al.* (2022) point out that, in many cases, the care of a child with ASD is the responsibility of the mother, which implies greater levels of burden for the mother. In this direction, the physical presence of the father does not show different results, due to the fact that he is not very participative in daily tasks with the children, a phenomenon that the authors call the "solitary act of caring". Similarly, the study by Dias (2017) showed that most care is provided by mothers, even if they are married. In this study, the author concluded that mothers experience moderate levels of overload.

Questions about the amount of time the caregiver has to themselves and the feeling that they could do more for the individual being cared for are constant among this group of mothers (who are usually the main caregivers) of children diagnosed with ASD. Barreto (2020) defined this condition as a risk factor for the mental health of mothers of children with ASD, specifically for those who are socially vulnerable. The author found that 38.9% of the study participants were moderately overloaded, and 44.4% were moderately to severely overloaded.

This stress damages the parental relationship and negatively influences child development (Brito; Faro, 2017). Behavioral problems, child well-being, negative parenting practices, health problems, or atypical development may be associated with the phenomenon of parental stress (Brito, 2016). Segeren (2015) noted that there are higher levels of stress in groups of parents of children with ASD, compared to those of children without the diagnosis. In this study, the author also checked parents' stress levels in relation to their children's oral communication or non-verbalization, concluding that communication, whatever it was, did not lead to differences in stress levels.

Perceived stress was also measured in a sample of parents of children with ASD in Malaysia, in which the average total score of perceived stress was considered higher than average. The highest rate of perceived stress occurred among caregivers who live far from the health institution, do not have transportation to take their child to the treatment center, and have a child with ASD with specific learning difficulties (Nik Adib *et al.*, 2019).

Christmann (2017), in a study with mothers of children with ASD, using the ISSL, identified the presence of stress symptoms in 84.6% of the participants. Of these, 86.7% were in the resistance phase, with predominantly psychological symptoms, which warns about the emotional health of primary caregivers.

In a sample of Italian parents, Operto *et al.* (2021) identified that parental stress is related to a greater number and severity of ASD symptoms perceived in the child. Variables such as the child's advanced age and a low repertoire of adaptive behaviors in socialization and communication are also associated with increased parental stress, as well as aggravating difficulties in the parent-child relationship.

Al-Farsi *et al.* (2016) concluded that there are significant rates of stress associated with anxiety and depression in parents of children with ASD in Oman. This condition characterizes an adverse psychological state, developed in the day-to-day care of the child, in which psychosocial needs are not met due to social vulnerability.

According to the Ministry of Health (2020), the prevalence of depression in Brazil is around 15.5%, and it is considered a highly prevalent medical problem in the population, in which the main victims are women. Andrade Filho and Dunningham (2019) state that Brazil is the country with the highest morbidity of depression in Latin America and the second highest in the Americas, behind only the United States, according to 2017 data from the World Health Organization (WHO).

Regarding depressive symptoms, Herrema (2017), in a study with families of autistic adults, highlights that family members reported higher levels of worry, depression, anxiety, stress, and poorer quality of life when caring for an autistic relative who has other concomitant mental health problems. This data highlights the extent to which the emotional health of caregivers of people with ASD can be affected throughout their daily care, considering the intense challenges they experience.

Clinical signs related to depression can also be identified in mothers of children with ASD who have higher levels of parental stress, including *cognitive deficits,* lack of energy, thoughts of death, pessimism, feelings of alienation, somatic symptoms, loss of interest, and low self-regulation skills. This moodiness and stress may be related to the insufficient social support received by mothers from the public authorities, considering that there is a possibility of increased parental need for self-sufficiency in the face of so many daily challenges (Baranczuk; Pisula, 2022). These challenges can add up to mixed signs and symptoms of depression and anxiety.

WHO data (2017) reveals that 9.3% of the Brazilian population suffers from anxiety, making Brazil the country with the highest prevalence in the world. Costa *et al.* (2019), in a study in the municipality of Pelotas/RS, identified an even higher prevalence of 27.4% in a sample of adults aged between 18 and 35 (N = 1,953). The authors also established factors that can increase the likelihood of developing anxiety, namely being female, having fewer years of schooling, having low socioeconomic status, having a history of chronic diseases, being tobacco users, and being alcohol abusers (Costa *et al.*, 2019).

In more complex clinical conditions, anxiety sensitivity can occur, which is a neuropsychological alteration related to fear of anxiety-related sensations. In this condition, there are intense concerns related to the somatic, social, and cognitive issues of anxiety (Behenck, 2018). The individual interprets anxiety situations as harmful and catastrophic, with an intense fear of physiological symptoms, cognitive lack of control, and other people's perception of the expression of the possible anxiety crisis.

The aim was to investigate the levels of overload and emotional changes, as well as coping in parents of children diagnosed with ASD, including screening for anxiety, depression, and perceived stress in parents of children diagnosed with ASD and their relationship with overload. It was also planned to identify the participants' main coping strategies and establish the possibility of a relationship between the results obtained from the instruments and sociodemographic data.

Method

Based on the Behavior Analysis approach, this is a cross-sectional *survey* with a non-probabilistic convenience sample.

Participants

Primary caregivers and parents of children diagnosed with ASD, aged up to 11 years and 11 months at the time of participation, were invited to take part in the study. The sample consisted of 50 participants, mothers (36), fathers (11), and grandparents (3) of children who attended three private clinics for the treatment of ASD and other developmental delays in a city in the interior of the state of São Paulo. The inclusion criteria were being literate, having a child aged up to 11 years and 11 months diagnosed with ASD, and belonging to any gender and any age. The exclusion criteria were not being literate or not completing all the survey instruments.

Instruments

a) Sociodemographic questionnaire

It was designed to characterize the participants based on the data provided in general questions about age, profession, income, family ties with the child with ASD, and general health.

b) Inventory of Coping Strategies - IEC (Folkman; Lazarus, 1985 adapted by Savoia; Santana; Mejias, 1996)

Translated and adapted into Portuguese by Savoia, Santana, and Mejias (1996), this instrument is used to assess how individuals deal with the internal or external demands of a stressful event. It is made up of 66 items that include thoughts and actions, the intensity of which is measured on a scale of 0 (no use) to 3 points (high use). The items that make up the inventory are divided into eight classification factors, which correspond to coping strategies: confrontation, withdrawal, self-control, social support, acceptance of responsibility, escape and avoidance, problem and positive re-evaluation (Savoia; Santana; Mejias, 1996).

c) Perceived Stress Scale - PSS-14 (Cohen *et al.*, 1983 adapted by Luft *et al.*, 2007)

It is an instrument that measures the degree to which individuals perceive situations as stressful. The content of this scale is made up of 14 items that are not related to specific contextual situations, which makes it easy to use in different age and cultural groups. Each of the 14 items, divided into positive and negative connotations, has answer options between zero and four, which can have scores from zero to 56.

d) Cognitive Anxiety Scale - ECOGA (Baptista *et al.*, 2020*)*

The ECOGA is a self-report instrument for adults aged 18 to 65 and aims to measure the degree of agreement with distorted beliefs related to anxiety. Before the factor analysis studies, the ECOGA was made up of 73 items, which were answered using a five-point Likert scale; these items were constructed based on the Cognitive Theory of Anxiety.

After investigating the psychometric properties of ECOGA (Baptista *et al.*, 2020), the final version with 31 items was defined according to the most appropriate theoretical and psychometric model, according to the authors. To investigate the type of cognitive content, ECOGA considers three main anxiety factors: negativism/pessimism, intolerance of vulnerability, and intolerance of uncertainty.

e) Baptist Depression Scale (Adult Version) - EBADEP-A (Baptista, 2012; Baptista; Gomes; Carneiro, 2013)

The EBADEP-A aims to assess the intensity of depression indicators in adults. However, later studies indicated that the scale correctly captures most depressive symptoms and can also be used to diagnose depression. The scale consists of 90 phrases that are presented in pairs, forming 45 items. Each item has one positive and one negative phrase, indicating the symptomatology in each item. The structure is in a four-point Likert format, between zero and three; the overall score is a minimum of zero and a maximum of 135 points. The lower the score, the lower the symptoms of depression.

f) Zarit Overload Inventory - ZBI (Zarit *et al.*, 1985 adapted by Taub *et al.*, 2004)

The ZBI is made up of 22 items on a scale of 0 to 4, according to the presence or intensity of an affirmative response, related to situations of possible overload in the care of an individual with a mental disorder. The questions refer to the caregiver's relationship with the patient, the caregiver's state of health, psychological aspects, well-being, finances, and social life.

Caregiver burden is assessed by the total score obtained from the sum of the points in each of the questions.

Procedure

We approached them personally to invite them to take part in the survey, which was carried out on the premises of the clinics, in a space reserved for filling in the instruments. It was also decided to schedule face-to-face participation via text messages sent by the clinics' secretaries. With the consent of the participants, data collection took place by appointment; while the children were in therapy, the parents voluntarily took part in the data collection.

Ethical procedures for research with human beings were respected, in accordance with CNS Resolution 466/12 and the Data Protection Act, which states that data is treated with professional standards of confidentiality, using the information only for academic and scientific purposes. The study was previously evaluated by the Research Ethics Committee of the Faculty of Sciences of the *Sao Paulo State University* - UNESP Bauru campus, CAAE: 58954822.4.0000.5398. Opinion No. 5.501.512.

It took two days to collect the data, the first of which was for the participants to read and sign the Informed Consent Form (ICF) with the applicator; they were then given access to the Sociodemographic Questionnaire, the Perceived Stress Scale and the Inventory of Coping Strategies, which were also filled in with guidance. On the second day, they were given the Cognitive Anxiety Scale, the Baptist Depression Scale - Adult Version, and the Zarit Overload Inventory, for which they were instructed to think of their child with ASD when answering it. The collection time was approximately 60 minutes on each day.

Data analysis

The data was analyzed using non-parametric statistical analysis, using the *software Statistical Package for the Social Sciences* (SPSS), version 24.0, with a significance level of 5%. The normality tests *Kolmogorov-Smirnov*, and *Shapiro-Wilk* indicated a non-normal distribution ($p < 0.05$), which justified the use of non-parametric inferential tests.

Spearman's correlation (Blair; Taylor, 2013) was used to verify the relationship between the variables of depressive symptoms, anxiety, and perceived stress with overload, coping, and sociodemographic data. The *Kruskall-Wallis* test was used for the analysis of variance to

compare three or more groups, and the *Mann-Whitney* test was used to compare the results of the instruments applied to up to two different groups.

Results

With regard to the averages for the participants' sociodemographic data, the age was 38 years (SD=5.97), two children, and the children diagnosed with ASD were, on average, four years old (SD=1.30). Regarding gender, 78% are women, and 22% are men. Most said they were married (92%), with single people (4%) representing the smallest proportion, as well as divorced people (4%). Mothers made up 72% of the participants, fathers 22%, and grandmothers 6%.

As for family income, 44.12% reported between three and five minimum wages, 35.29% more than five minimum wages, and 20.59% up to three minimum wages. All said they had their own car and health insurance. Regarding religion, 90% said they were practicing. In terms of well-being and quality of life, 66% did not practice physical activity, 98% did not practice meditation, 92% declared themselves non-smokers, and 70% reported not consuming alcohol. In terms of general health, 82% had no chronic illnesses, and 64% did not take medication continuously.

The participants' education level is distributed as follows: 52% have completed high school, and 48% have completed higher education. With regard to mental health history, 76% did not report having a medical diagnosis of emotional disorders. The level of support of the child with ASD stands out as an important marker, with 50% of caregivers reporting that the child falls into level two of support, which implies non-oral children and/or those with complex communication needs. In addition, 48% of caregivers care for a child at level one of support, and 2% care for a child at level three of support. Below is the frequency distribution of the results of the EBADEP-A, ECOGA, and EEP instruments used to assess depressive symptoms, anxiety, and perceived stress, respectively.

Table 1 - Prevalence of depression, anxiety and stress in the parents and grandparents of the sample surveyed (N=50)

Instrument	Average score		
	Mother	Dad	Grandma
EBADEP-A	44,14	35,45	43,00
ECOGA - General	62,30	52,27	56,66
ECOGA - F1 Negativism/Pessimism	14,55	12,81	13,00
ECOGA - F2 Intolerance of vulnerability	30,66	23,45	24,66
ECOGA - F3 Intolerance of uncertainty	17,03	16,00	19,00
EEP - General	29,58	28,45	19,66

Source: Prepared by the authors.

The average score on the EBADEP-A, according to the instrument's technical manual, classifies the sample as having minimal depressive symptoms. The prevalence of anxiety (ECOGA) shows that the participants had a predominant factor of intolerance to vulnerability during the data collection period. Mothers had overall anxiety scores up to 10 points higher than those obtained by fathers. According to the EEP, the participants do not perceive themselves as stressed individuals, which is expressed by the average score for all the types of bonds the participants have with the child diagnosed with ASD (mother, father, or grandmother), taking into account the instrument's classification instructions.

Table 2 shows the prevalence of overload in the participants, considering the four possible classifications of the ZBI and the three types of bond with the child diagnosed with ASD. The percentage of overload is also presented according to the sum of the frequency of the participants' classification in each of the links.

Table 2 - Prevalence and classification of overload in mothers, fathers, and grandparents, according to the Zarit Overload Inventory - ZBI (N = 50)

Classification - ZBI	Fr. of classification according to link			%
	Mother	Dad	Grandma	
Absence	9	3	1	26
Moderate	14	5	2	42
Moderate to severe	11	3	0	28
Severe	2	0	0	4

Source: Prepared by the authors.

The sum of the percentages of the three ZBI classifications of moderate to severe burden shows that 74% of the participants report significant levels of burden, considering the three

possible links with the child with ASD: mother, father, or grandmother. More than 50% of the participants, when grouped by job title, also showed significant levels of moderate to severe overload.

Table 3 shows the participants' average scores on the ZBI, separated by a bond with the child, with the correction made as suggested by the authors in the process of adapting the instrument. By analyzing the average score, it is possible to see the level of overload in each of the groups of participants.

Table 3 - Mean score (M) and standard deviation (SD) of mothers, fathers, and grandparents on the Zarit Overload Inventory - ZBI (N = 50)

	Mother		**Parent**		**Grandma**	
Score	M	DP	M	DP	M	DP
ZBI	34,19	15,13	29,82	14,24	27,00	11,00

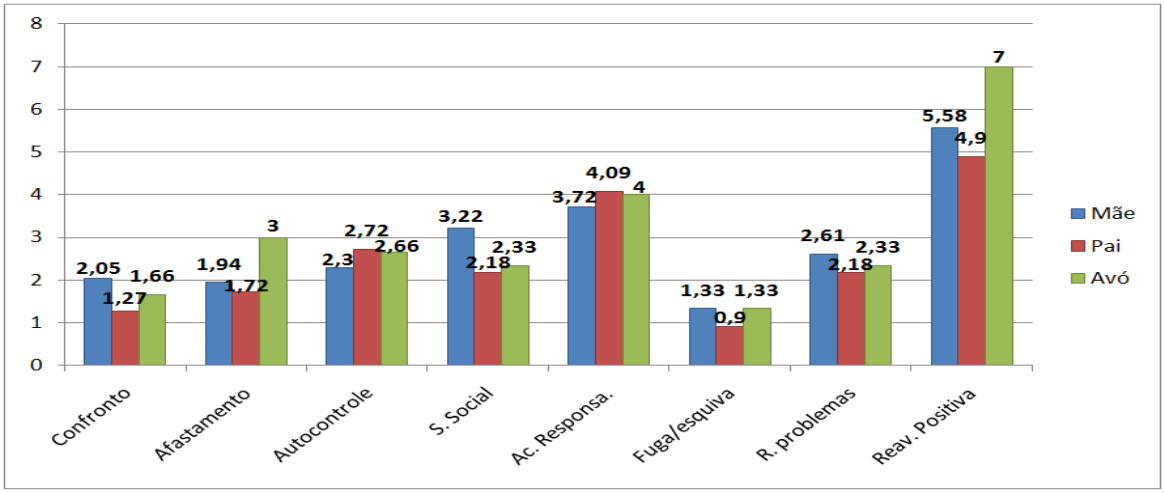
Source: Prepared by the authors.

It can be seen that mothers have a higher average ZBI score (M = 34.19) than fathers (M = 29.82) and grandparents (M = 27.00). This data shows that in the group of caregivers, mothers may experience a greater burden in the process of caring for children with ASD. According to the standards for correcting the ZBI, values between 21 and 40 points indicate moderate overload, a classification that can be considered for the three groups of participants if separated by bond with the child or by analyzing the sample in general.

Still investigating the prevalence of overload in caregivers separated by groups, the average score of the participants in the ZBI was counted when divided by the sociodemographic indicator of income. We chose to select this variable because of its significance in previous studies found in the databases, in order to compare previous and current research.

Figure 1 shows the main coping strategies used by the participants, which were reported using the *Coping Strategies Inventory* (IEC). For correction, the frequency of responses to the use of the strategies listed in the instrument was taken into account. Answers marked between "0" and "1" were considered "no"; answers marked between "2" and "3" were considered "yes". The frequency shown in Figure 1 has only been described for the answers classified as "yes".

Figure 1 - Graph with the average of the main coping strategies used by parents and grandparents according to the IEC[4]



Source: Prepared by the authors.

By analyzing Figure 1, it is possible to understand that according to the data collected with the IEC, the highest average scores for the use of coping strategies were for the items related to "Acceptance of responsibility" and "Positive re-evaluation". For the acceptance of responsibility, the IEC lists the following items: I criticized myself, I reprimanded myself; I apologized or did something to repair the damage; I understood that I caused the problem; I looked to past experiences for a similar situation; I promised myself that things will be different next time; I found some different solutions to the problem; I mentally analyzed what to do and what to say. For positive re-evaluation, the inventory defines the items: inspired me to do something creative; changed or grew as a person in a positive way; came out of the experience better than I expected; found new beliefs; rediscovered what is essential in life; modified aspects of the situation so that everything worked out in the end; changed something about myself, modified myself in some way; prayed; thought of a person I admire and how they would resolve the situation and took them as a model (Folkman; Lazarus, 1985 adapted by Savoia; Santana; Mejias, 1996).

For coping strategies related to confrontation, it is possible to highlight the average score on the IEC items separated according to the child's level of support: Level 1 (M = 21.02), Level 2 (M = 28.82) and Level 3 (M = 50.00). It's important to consider that these strategies have the following statements as items: I tried to find the person responsible for changing their mind; I

[4] Translation from left to right: Confrontation; Withdrawal; Self-control; Social S.; Responsible Ac.; Escape/avoidance; R. Problems; Positive Re.

showed my anger to the people who caused the problem; I vented my feelings in some way; I faced it as a big challenge; I did something very risky, I tried to get away from people in general, and I took my anger out on someone else.

Table 4 shows the correlation between the variables of overload, depression, anxiety, and perceived stress in the participants, according to Spearman's correlation test. This analysis sought to highlight possible associations between overload and emotional health indicators.

Table 4 - Correlation between overload, depression, anxiety and perceived stress in survey participants (N = 50)

	Depression	**Anxiety General**	**Anxiety Neg/pessim.**	**Anxiety Intol. Vul.**	**Stress perceived**
Overload	**0.89****	0,64**	0,54**	0,61**	0,65**
Depression	1	**0.75****	0,66**	**0,70****	0,67**
General anxiety		1	**0.77****	**0.89****	0,59**
Perceived stress					1

** Strength of correlation magnitude.
Source: Prepared by the authors.

According to Spearman's correlation test, there was a strong correlation (above 0.69) between the variables of overload, depression, general anxiety, and the vulnerability intolerance factor. It was found that the lower the burden, the lower the score for depression; likewise, the lower the score for depression, the lower the scores for general anxiety and the vulnerability intolerance factor. The anxiety factor "intolerance of vulnerability" also correlated with lower depression scores.

There was a moderate correlation (between 0.40 and 0.69) between the variables of overload, general anxiety, intolerance of vulnerability, perceived stress, negativism-pessimism, and depression. The lower the score for overload, the lower the scores for general anxiety, for the anxiety factor "intolerance of vulnerability", and for perceived stress. With regard to depression, the lower the scores for this condition, the lower the scores for the anxiety factor "negativism/pessimism" and for perceived stress.

As for possible differences in average responses between groups, only the schooling variable showed significant differences in average responses between groups. In this sense, participants with complete higher education used problem-solving more as a coping strategy than participants with lower levels of education (incomplete higher education and complete secondary education).

Discussion

Most of the sample was made up of females who are mothers and grandmothers, the main caregivers of children diagnosed with ASD. Male parents accounted for only 22% of the sample, which confirms that the prevalence of care is still more the responsibility of women, in line with Vilanova *et al.* (2022).

When analyzing the sociodemographic data, it was possible to consider that the lower the income of the participants, the higher the levels of overload. In this study's sample, which was mostly made up of women, it can be understood that being the mother of a child with ASD and having a lower income includes women in two risk factors for developing overload. These factors complement the findings of Dias (2017), who mentions the prevalence of moderate overload among mothers due to the difficulties faced, the care routine, the impact of the diagnosis, and the prejudices in society. The socio-economic differences between the mothers can be included as difficulties.

Barreto (2020), in a study on the prevalence of overload in mothers of children with ASD, reported social vulnerability as a risk factor for overload, and also pointed out that most of the sample had severe overload. In this study, there was a lower prevalence of severe overload, possibly due to the favorable socio-economic conditions of the participants: average income of more than three minimum wages, all had their vehicles, and their children had health insurance that covered specialized therapies.

Another sociodemographic fact that stood out was the level of support of the children with ASD, where 50% were at level two and 2% at level three. This means that more than half of parents live with children who have major difficulties in communication and social interaction. Regarding communication, Segeren (2015) described that difficulties in oralizing and verbalizing did not correlate with the parents' stress levels, but when comparing with the data from this research, it is evident that the children's poor communication may have influenced the parents' higher levels of burden, although stress was not significant either.

No information was found in previous literature on coping strategies in parents of children with ASD. In this study's sample, there were higher scores for coping strategies related to accepting responsibility and positive re-evaluation, according to the items described by Savoia, Santana, and Mejias (1996) in their translation of the *Coping Strategies Inventory*.

According to Lazarus and Folkman's (1984) coping model, the strategy items used by participants can include accepting responsibility as a problem-oriented coping and positive reappraisal aimed at the respondent's emotions. In this way, it can be understood that

the participants may act to solve the problems related to their children with ASD but that they also consider their own emotional and affective stability, which may direct them toward two stress variables: their own difficulties and the difficulties of their children.

An important difference noted in the sociodemographic analysis was that parents with completed higher education used more problem-solving strategies. This can put them at greater risk of developing stress, as they are focused on the problem and the possibilities of solving it.

Even with the risk factor for developing stress, the participants did not obtain high scores for perceived stress. This differs from Brito (2016), who highlighted atypical development as one of the factors for the development of stress in parents. With the use of the same instrument used in this research, the findings also differ from what was analyzed by Nik Adib *et al.* (2019) in Malaysia, where there were high scores of perceived stress among parents of children with ASD.

With data collected using different instruments, other researchers have also obtained divergent responses to those analyzed in this study, such as the research carried out by Christmann (2017) using the ISSL, Operto *et al.* (2021) with the Parental Stress Inventory and Al-farsi *et al.* (2016) using the DASS-21. There is a possibility that the coping strategies of the parents in this study were sufficient not to make the state of stress chronic throughout the daily routine of caring for their children, or that this did not happen because of the young age of the children. Perhaps, when they are older and if the treatment has not shown relevant results in recovering from developmental delays, the stress condition may become chronic.

Herrema (2017) explained that the atypical development of individuals with ASD can have an impact on the emotional health of parents, especially when the neurodevelopmental condition is added to other clinical conditions. Parents may have a higher prevalence of depression with their adult children. The data obtained from this study, carried out with parents of children, shows that the participants had scores equivalent to minimal depressive symptoms or even no depressive symptoms.

The absence of depression in the participants contrasts with the norm reported by the Ministry of Health (2020), which indicated a high prevalence of depression in the Brazilian population in general. It also diverges from Andrade Filho and Duningham (2019), who stated that, in 2017, Brazil had the highest morbidity rate due to depression in Latin America. It is important to note that, even in the face of a specific condition of overload, the participants maintained the absence of depressive symptoms. Once again, it is possible to associate the regular financial status of the sample with the low prevalence of disorders and other emotional

conditions, suggesting that a good socioeconomic status can act as a protective factor against emotional disorders in parents of children with ASD. This result corroborates what Silva *et al.* (2021) describe, pointing out that unfavorable socioeconomic conditions are risk factors for the development of psychopathologies, as well as being single and not having a perceived support network.

Most of the participants in the survey reported being married, which may constitute a consistent support network that supports them in their daily lives with the child. This corroborates what Baranczuk and Pisula (2022) found about social support being related to the prevalence of emotional conditions, such as depression and parental stress, in mothers of children with ASD.

Unexpected situations, such as those experienced during the COVID-19 pandemic, can also be an important factor in increasing rates of depression, anxiety, and stress in parents of children with ASD, as discussed by Silva *et al.* (2021). Gaiato, Silveira, and Zotesso (2022) explained the challenges faced by children with ASD during the pandemic, which reinforces the hypothesis of worse emotional health conditions for parents during this period. As this study was carried out in the final period of the health crises involving COVID-19, it may have explained the low prevalence of depressive symptoms in the participants.

The low prevalence of depression in the sample, observed through the correlation test, indicates a strong relationship between the levels of overload and the score on the instrument used to measure depressive symptoms, suggesting a possible association between overload and depression in individuals. In this context, the lower the score for depression, the lower the scores on the overload scale. This relationship was also observed between depressive symptomatology and scores for general anxiety.

With regard to the findings on anxiety, it can be said that the lower the depressive symptoms, the less likely the individual is to show symptoms of anxiety, specifically in the cognitive components of negativism/pessimism and intolerance of vulnerability. Behenck (2018) highlights the cognitive factors of anxiety, which were specifically addressed in this study, using the scale developed by Baptista *et al.* (2020), the ECOGA.

The higher scores on items related to negativism/pessimism suggest that the individual may make catastrophic and pessimistic evaluations about themselves and events. In this way, they often see situations as more threatening and negative than they really are, perceiving themselves as incapable of dealing with them. According to the ECOGA authors, when experiencing intolerance of vulnerability, people may interpret being vulnerable as being weak,

fragile, or unable to function effectively (Baptista *et al.*, 2020). So, they tend to regulate their emotions by avoiding talking or thinking about situations that might make them anxious, resorting to distraction and emotional detachment.

Both factors can be detrimental to parents who experience the routine of caring for children with ASD, considering that daily life involves various unforeseen events, consultations with health professionals, diagnostic comorbidities, and constant uncertainty about their children's development, limiting their prospects for the future.

Excessive concern and the search for security are not exclusive to the sample in this survey. According to the World Health Organization (WHO, 2017), the Brazilian population has the highest prevalence of anxiety in the world. This finding is corroborated by Costa *et al.* (2019), in a survey of the adult population of Pelotas (RS).

Adverse situations can also trigger anxiety in parents, such as obstacles to health insurance. Many operators impose excessive bureaucracy in order to offer full coverage of treatment for ASD and often don't offer the appropriate specialized service, such as therapies based on ABA science, which becomes a complaint from parents. In addition to anxiety, the caregiver may feel powerless in the face of this challenge, increasing the risk of stress and overload.

The low scores for depression and stress show that the emotional health of the participants was not compromised, possibly due to the favorable socioeconomic conditions and also because they were all treated by health insurance companies, in private clinics, not depending on the public service. This data may also be related to the development of effective coping strategies to deal with the demands of the children cared for by the participants.

This study has some limitations, such as the social and economic profile of the individuals. The sample was one of convenience, but with a significant number of participants, considering the limited location, in the interior of the state of São Paulo, where the study was carried out. Further research is suggested by reapplying the instruments with a larger number of caregivers, with children being cared for in public health facilities.

Final considerations

This study found that being responsible for the primary care of a child diagnosed with Autism Spectrum Disorder (ASD) did not significantly affect the emotional health of caregivers during the data collection period. However, overload was prevalent among mothers. When facing the challenges of the care routine, mothers, fathers, and grandparents developed functional coping strategies, which may have contributed to emotional stability in relation to indicators of stress and depression.

This consideration was based on the analysis of the levels of burden and emotional changes of the caregivers, as well as the coping strategies used in critical moments of daily life with the children. The investigations were carried out by tracking the prevalence of anxiety, depression, and perceived stress, associating this data with overload indices.

It was observed that coping strategies, such as accepting responsibility and positive reassessment, were widely used by caregivers, helping them in challenging situations. In addition, favorable socioeconomic conditions acted as important protective factors for the prevention of emotional disorders.

This study has contributed to research into the overload of primary caregivers of children with ASD, as well as highlighting the ways in which they deal with the complex task of caring. The analysis of possible relationships between different emotional health variables, using various instruments, expands knowledge on the subject and lays the foundations for future research.

It is suggested that further studies be carried out on the same subject and method, including participants with different socioeconomic profiles, users of public services, or caregivers of children who are not receiving adequate interventions. Furthermore, further research into the risk and protective factors for the emotional health of parents of children with ASD is essential in order to promote preventive and psychoeducational interventions that are widely disseminated and accessible.

REFERENCES

AL-FARSI, O. A.; AL-FARSI, Y. M.; AL-SHARBATI, M. M.; AL-ADAWI, S. Stress, anxiety, and depression among parents of children with autism spectrum disorder in Oman: a case-control study. **Neuropsychiatr Dis Treat**, *[S. l.]*, v. 4, n. 12, p. 1943-51, 2016. DOI: 10.2147/NDT.S107103. PMID: 27536117; PMCID: PMC4977076. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4977076/. Accessed in: 12 Nov. 2022.

AMERICAN PSYCHIATRIC ASSOCIATION. **Manual diagnóstico e estatístico de transtornos mentais**: DSM-5-TR. Porto Alegre: Artmed, 2023. 5. Ed.

ANDRADE FILHO, A. S.; DUNNINGHAM, W. A. A Pandemia da Depressão. **Revista Brasileira de Neurologia e Psiquiatria**, *[S. l.]*, v. 23, n. 3, 2019. Available at: https://revneuropsiq.com.br/rbnp/article/viewFile/579/198. Acessos em: 06 Nov. 2022.

BAPTISTA, M. N. **Escala Baptista de Depressão (Versão Adulto) – EBADEP-A**. São Paulo: Vetor, 2012.

BAPTISTA, M. N.; FALCONE, E. M. de O.; VIEGAS, M. P.; OLIVEIRA, E. R.; KRIEGER, S.; PEREIRA, L. B.; ALVES, A. J. de C. P.; PELUSO, M. L.; SILVA, F. T. Estrutura Interna da Escala Cognitiva de Ansiedade (ECOGA). **Psico-USF** [online], *[S. l.]*, v. 25, n. 4, p. 751-762, 2020. ISSN 2175-3563. DOI: https://doi.org/10.1590/1413/82712020250413, Accessed in: 29 Nov. 2021.

BAPTISTA, M. N.; GOMES, J. O.; CARNEIRO, A. M. Exploratory Study of the Diagnostic Abilities of the Baptista Depression Scale Adult Version (EBADEP-A). **Paidéia (Ribeirão Preto)**, *[S. l.]*, v. 23, n. 56, p. 301-309, 2013. DOI: 10.1590/1982-43272356201304. Available at: https://www.revistas.usp.br/paideia/article/view/75844. Accessed in: 21 Nov. 2021.

BARAŃCZUK, U.; PISULA, E. Parental stress and symptoms of depression: a preliminary report. **Int J DevDisabil**, *[S. l.]*, v. 68, n. 4, p. 445-453, 2020. DOI: 10.1080/20473869.2020.1797450.

BARRETO, A. F. **Indicadores de risco e proteção para a saúde mental de mães de crianças com Transtorno do Espectro do Autismo em situação de vulnerabilidade social**. 2020. 99f. Dissertação (Mestrado em Distúrbios do Desenvolvimento), Universidade Presbiteriana Mackenzie, São Paulo, 2020. Available at: https://dspace.mackenzie.br/handle/10899/28568. Accessed in: 12 Nov. 2022.

BEHENCK, A. S. **Sensibilidade à ansiedade e transtorno de pânico**: avaliação do impacto da terapia cognitivo-comportamental em grupo. 2018. 80f. Tese (Doutorado em Enfermagem) – Universidade Federal do Rio Grande do Sul, Escola de Enfermagem, Porto Alegre, 2018. Available at: https://lume.ufrgs.br/handle/10183/196158. Accessed in: 12 Nov. 2022.

BLAIR, R. C.; TAYLOR, R. A. Análise de correlação. *In*: BLAIR, R. C.; TAYLOR, R. A. **Bioestatística para ciências da saúde.** São Paulo: Pearson Education do Brasil, 2013.

BRASIL. **Lei nº 13.709 (Lei Geral de Proteção de Dados Pessoais [LGPD])**, de 14 de agosto de 2018, dispõe sobre a proteção de dados pessoais e altera a Lei nº 12.965, de 23 de

abril de 2014. Available at: http://www.planalto.gov.br/ccivil_03/_ato2015-2018/2018/lei/l13709.htm. Accessed in: 29 Nov. 2021.

BRASIL. Ministério da Saúde. Departamento de Atenção Básica. Coordenação Geral de Atenção Domiciliar. **Melhor em casa**: a segurança do hospital no conforto do seu lar – Caderno de Atenção domiciliar. Brasília, DF, 2012. v. 1.

BRITO, A. **Estresse parental e práticas socioeducativas parentais em pais/mães de filhos com e sem diabetes *mellitus* tipo 1**. 2016. 117 f. Dissertação (Pós-Graduação em Psicologia Social) - Universidade Federal de Sergipe, São Cristóvão, 2016. Available at: https://ri.ufs.br/handle/riufs/6019. Accessed in: 13 Nov.2022.

CHRISTMANN, M. **Associação entre estresse, rede social de apoio e crenças parentais em mães de crianças com TEA**. 2017. 62f. Dissertação (Mestrado em Distúrbios do Desenvolvimento), Universidade Presbiteriana Mackenzie, São Paulo, 2017. Available at: http://dspace.mackenzie.br/handle/10899/22729. Accessed in: 12 Nov. 2022.

COHEN, S.; KAMARCK, T.; MERMELSTEIN, R. A Global Measure of Perceived Stress. **Journal of Health and Social Behavior**, *[S. l.]*, v. 24, n. 4, p. 385–396, 1983. DOI: https://doi.org/10.2307/2136404.

CONSELHO NACIONAL DE SAÚDE (BRASIL). **Resolução n º 466, de 12 de dezembro de 2012**. Brasília, 2012. Available at: https://bvsms.saude.gov.br/bvs/saudelegis/cns/2013/res0466_12_12_2012.html. Accessed in: 29 Nov. 2021

COSTA, C. O; BRANCO, J. C.; VIEIRA, I. S.; SOUZA, L. D. de M.; SILVA, R. A. Prevalência de ansiedade e fatores associados em adultos. **Jornal Brasileiro de Psiquiatria**, *[S. l.]*, v. 68, n. 2, p. 92–100, Apr. 2019. DOI: 10.1590/0047-2085000000232.

DIAS, C. C. V. **Mães de crianças autistas**: sobrecarga do cuidador e representações sobre o autismo. Dissertação (Mestrado em Psicologia Social), Universidade Federal da Paraíba, João Pessoa, 2017. Available at: https://repositorio.ufpb.br/jspui/handle/tede/9081. Accessed in: 12 Nov. 2022.

FOLKMAN, S.; LAZARUS, R. S. If it changes it must be a process: study of emotion and coping during three stages of a college examination. **Journal of Personality and Social Psychology**, *[S. l.]*, v. 48, n. 1, p. 150-70, 1985. DOI: 10.1037//0022-3514.48.1.150.

GAIATO, M. H. B.; SILVEIRA, R. R.; ZOTESSO, M. C. Reflexos comportamentais da Covid-19 em crianças com autismo: Revisão sistemática. **Doxa: Rev. Bras. Psico. e Educ.**, Araraquara, v. 23, n. 00, e022012, 2022. e-ISSN: 2594-8385. DOI: 10.30715/doxa.v23i00.16711

GAIATO, M. H. B.; ZOTESSO, M. C.; FERREIRA, L.; SILVEIRA, R. da R.; DIODATO, R. Transtorno do espectro autista: Diagnóstico e compreensão da temática pelos responsáveis. **Revista Contexto & Saúde**, *[S. l.]*, v. 22, n. 46, 2022. Available at: https://revistas.unijui.edu.br/index.php/contextoesaude/article/view/13209. Accessed in: 05 Apr. 2023.

HERREMA, R.; GARLAND, D.; OSBORNE, M.; FREESTON, M.; HONEY, E.; RODGERS, J. Mental Wellbeing of Family Members of Autistic Adults. **J Autism Dev Disord**, *[S. l.]*, v. 47, p. 3589–3599, 2017. DOI: 10.1007/s10803-017-3269-z.

LAZARUS, R., FOLKMAN, S. **Stress appraisal and coping**. New York: Springer Publishing, 1984.

LUFT, C. D. B.; SANCHES, S. de O.; MAZO, G. Z.; ANDRADE, A. Versão brasileira da Escala de Estresse Percebido: tradução e validação para idosos. **Revista de Saúde Pública Revista de Saúde Pública**, *[S. l.]*, v. 41, n. 4, p. 606–615, ago. 2007. DOI: 10.1590/S0034-89102007000400015.

MAENNER, M. J. *et al*. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. **MMWR Surveill Summ**, *[S. l.]*, v. 72, n. 2, p. 1-14, 2023. DOI: 10.15585/mmwr.ss7202a1.

MINISTÉRIO DA SAÚDE. Depressão. *In*: MINISTÉRIO DA SAÚDE. **Saúde de A a Z:** D. [S. l.], 16 Nov. 2020. Available at: https://www.gov.br/saude/pt-br/assuntos/saude-de-a-az/d/depressao-1/depressao. Accessed in: 06 Nov. 2022.

NIK ADIB, N. A.; IBRAHIM, M. I.; RAHMAN, A. A.; BAKAR, R. S.; YAHAYA, N. A.; HUSSIN, S.; MANSO, W. N. A. W. Perceived Stress among Caregivers of Children with Autism Spectrum Disorder: A State-Wide Study. **Int. J. Environ. Res. Public Health**, *[S. l.]*, v. *16*, n. 8, p. 1468, 2019. https://doi.org/10.3390/ijerph16081468. Accessed in: 10 Oct. 2021.

OPERTO, F. F.; PASTORINO, G. M. G.; SCUOPPO, C.; PADOVANO, C.; VIVENZIO, V.; PISTOLA, I.; BELFIORE, G.; RINALDI, R.; DE SIMONE, V.; COPPOLA, G. **Adaptive Behavior, Emotional:** behavioral problems and parental stress in children with autism spectrum disorder. **Front Neurosci**, *[S. l.]*, v. 25, n. 15 p. 751465. DOI: 10.3389/fnins.2021.751465.

SAVOIA, M. G.; AMADERA, R. D. Utilização da versão brasileira do inventário de estratégias de coping em pesquisas da área da saúde. **Psicol. Hosp.**, São Paulo, v. 14, n. 1, p. 117-138, 2016. Available at: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1677-74092016000100007&lng=pt&nrm=iso. Accessed in: 12 Oct. 2022.

SAVOIA, M. G.; SANTANA, P. R.; MEJIAS, N. P. Adaptação do inventário de Estratégias de Coping de Folkman e Lazarus para o português. **Psicol. USP**, São Paulo, v. 7, n. 1-2, p. 183-201, 1996. Available at: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1678-51771996000100009&lng=pt&nrm=iso. Accessed in: 04 Jan. 2022.

SEGEREN, L. **Correlação entre a oralidade de crianças com distúrbios do espectro do autismo e o nível de estresse de seus pais**. 2015. Dissertação (Mestrado em Ciências da Reabilitação) - Faculdade de Medicina, Universidade de São Paulo, São Paulo, 2015. doi:10.11606/D.5.2015.tde-12062015-090614. Accessed in: 10 Oct. 2021.

SILVA, T. M.; COUTO, L. M. F.; BAPTISTA, M. N. Níveis de Depressão, Ansiedade e Estresse em Familiares Cuidadores de Crianças Com e Sem Diagnóstico de TEA Durante a Pandemia de COVID-19. **Contextos Clínicos**, *[S. l.]*, v. 14, n. 3, set/dez. 2021. DOI: 10.4013/ctc.2021.143.12. Available at: http://revistas.unisinos.br/index.php/contextosclinicos/article/view/23478/60748859. Accessed in: 11 Nov. 2022.

TAUB, A.; ANDREOLI, S. B.; BERTOLUCCI, P. H. Dementia caregiver burden: reliability of the Brazilian version of the Zarit caregiver burden interview. **Cadernos de Saúde Pública** [online], v. 20, n. 2, p. 372-376, 2004. DOI: 10.1590/S0102-311X2004000200004.

VILANOVA, J. R. S.; CARNEIRO, C. T.; ROCHA, K. N. de S.; BRITO, M. de A.; ROCHA, R. C.; COSTA, A. de C.; BEZERRA, M. A. R. Burden of mothers of children diagnosed with autism spectrum disorder: mixed method study. **Revista Gaúcha de Enfermagem**, v. 43, 2022. DOI: 10.1590/1983-1447.2022.20210077.

WORLD HEALTH ORGANIZATION (WHO). **Depression and other common mental disorders**: global health estimates. Genebra: WHO; 2017.

ZARIT, S. H.; ORR, N. K.; ZARIT, J. M. **The hidden victims of Alzheimer's disease:** families under stress. New York: NYU Press, 1985.

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