ORIGINAL ARTICLE

Stress in parents of children diagnosed with autism spectrum disorder in a private institution, Lima, Peru, 2022

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ABSTRACT

Objective: To determine the level of stress in parents of children diagnosed with autism spectrum disorder (ASD) at the Instituto para el Desarrollo Infantil (Institute for Child Development) - ARIE, San Juan de Lurigancho (SJL) branch, 2022.
Materials and methods: A descriptive and cross-sectional study at the Instituto para el Desarrollo Infantil - ARIE, SJL branch, in Lima, Peru. All parents (n = 79) of children aged ≤ 8 years with ASD who were undergoing therapy in 2022 were included; therefore, sampling was not required. The PSI/SF (Parenting Stress Index, Short Form) was used to measure stress in parents. This instrument has been used in other research studies, validating it with a Cronbach's alpha coefficient of 0.93 to determine parental stress. The variables *sex of the parent, sex of the child, age, level of education* and *type of family* were analyzed with SPSS software, version 27, using descriptive statistics and chi-square test.
Results: A total of 79 parents were surveyed: average age 35.20, *SD* 5.217, predominantly females (68.35 %). Of the parents, 73.41 % had higher education. Parental stress perceived by mothers (83.33 %) was slightly higher than that of fathers (60 %) (p < 0.05). There is an association between the level of parental stress and the sex of the child, with males (82.1 %) causing more stress compared to females (60.9 %). Single-parent families have shown a higher level of stress, with 95.46 %, as opposed to two-parent families, with 64.42 %) (p < 0.05).
Conclusions: Most parents of children with ASD experience clinically significant stress, with scores greater than 90, with mothers having a higher level of stress. There is a significant association between parental stress and the sex of the child and the type of family (p < 0.05).

Keywords: Sex; Autism Spectrum Disorder; Family (Source: MeSH NLM).

INTRODUCTION

Having a child with a severe physical or mental disability is a potential disruptive element in the family dynamics [1,2].

Approximately one in every 100 children is diagnosed with autism spectrum disorder (ASD) worldwide [3]. From birth, children with ASD are apparently healthy; however, as the years go by, they begin to present certain behaviors that especially worry and disturb parents, who may feel guilt, reproaches and stress, and may even argue about the origin of such disorder [1,4-6]. This is because children diagnosed with ASD can cause important changes in parents' lives and in their social relationships, resulting in chronic stress [1,7,8]. It is important to state that stress is the body's response to a challenge or demand. This response can be positive in dangerous situations, as it keeps us alert, but inadequate management can lead to feelings of anxiety, anguish or depression [1].

ASD is a neurodevelopmental disorder with a biological basis, characterized by deficits in the areas of communication and social interaction [5,9,10]. Repetitive behavior patterns and restricted activities are also observed [11-13].

For more than 20 years, research on autism has not only sought to focus on studying the characteristics of ASD but has also analyzed the stress associated with having a child with this condition [4,14].

In 2011, Bueno Hernández conducted a descriptive cross-sectional study in which she described data obtained from 30 parents who were members of the Asociación de Padres y Amigos de Personas con Autismo del Perú (Aspau-Perú, Association of Parents and Friends of People with Autism of Peru). She found that more than 50 % of the parents had a negative reaction to the diagnosis of their children. In addition, it was observed that 63.3 % of the parents, mostly mothers, resigned from their jobs to care for their children. Furthermore, 70 % of the parents faced the situation together, while 26.7 % ended up in marital separation, with stress being the most common manifestation in this group [15].

In 2012, in Lima, Peru, Pineda Gonzales carried out a descriptive correlational study on parental stress and coping styles among parents of children with autism ASD.

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The sample included 58 parents (13 men and 45 women) whose children had been diagnosed with ASD. The results showed that 89.7 % had significant stress. In addition, it was observed that 92.3 % of fathers had significant stress compared to 88.9 % of mothers [16].

In 2014, Ximena Mendoza Álvarez studied the association between stress and optimism among parents of children with ASD. The study was conducted at an education center specialized in autism in the city of Lima, Peru. The results showed high clinical significance for both the total parental stress scale (87.88 %) and its components: parental distress (75.76 %), dysfunctional parent-child interaction (93.94 %) and childcare stress (69.7%) [17].

In 2017, Arphi et al. performed a descriptive correlational study involving parents of children diagnosed with autism who were members of Aspau-Perú. The sample included 80 parents. The results revealed that 72 % and 12 % presented moderate and severe levels of stress, respectively.

In Jordan, Khamis Alnazly and Amjed Abojedi, in 2019, conducted a cross-sectional study including 123 Jordanian parents caring for children diagnosed with ASD. They found moderate levels of stress, negative life changes and borderline depression and anxiety. The perceived burden of caregiving tasks was negatively correlated with depression and anxiety, while anxiety levels were positively correlated with depression ($p < 0.001$) [19].

In 2020, Enriquez Carranza and Rodriguez Ticona performed a descriptive correlational study on coping strategies and parental stress. They used a convenience sample of 35 parents in Arequipa, Peru, and found that 97.10 % presented significant stress. Of the three dimensions analyzed by their instrument, the highest stress was found in "difficult child," which focuses on the child's behavior and its particularities [20].

Studies on the impact of autism on families have shown that impairment in social and behavioral functions has significant effects on family dynamics: sleep disturbances, hyperactivity, hypersensitivity, behavioral problems and eating disorders are factors studied as potential sources of stress for family members of individuals with autism [4,14].

Peru remains behind in terms of addressing ASD compared to Spain, which manages many programs, e.g., MEJORA, that promotes the well-being of both children with ASD and their families [21,22]. The well-being of parents is important as parent-mediated intervention for their children improves aspects such as communication and the symptoms of ASD itself [23].

This study aims to assess the impact of parental stress on families with autistic children, considering both its economic and emotional consequences. One of the highlighted aspects is the high cost of the therapies for the development and well-being of children with autism. These therapies represent a significant financial burden for parents, which can cause more stress within the family. In addition, the education of children with autism can be a challenge as their acceptance in schools is not always guaranteed, and even if accepted, the quality of education may not be adequately adapted to their specific needs.

This situation leads to parents being forced to seek additional therapies to help their children cope with the social and emotional challenges associated with autism. However, the ongoing care and support of autistic children can be overwhelming for parents, who also experience high levels of stress. This can result in a cycle of stress for both parents and children: due to their own stress, parents may have difficulty providing the necessary emotional support or may manifest irritability, which, in turn, can negatively affect the children's progress in therapy and overall development. Therefore, it is essential to understand and address the impact of parental stress presented by parents of children diagnosed with ASD at the Instituto para el Desarrollo Infantil (Institute for Child Development) - ARIE, San Juan de Lurigancho (SJL) branch, in 2022.

MATERIALS AND METHODS

Study design and population

An observational, descriptive and cross-sectional study was conducted at the Instituto para el Desarrollo Infantil-ARIE, SJL, in Lima, Peru. ARIE is a private institution that provides specialized care to patients requiring expert treatment in neurodevelopment and rehabilitation.

This research involved parents whose children diagnosed with ASD under 8 years of age were undergoing therapy in 2022 at the Occupational Therapy service. Sampling was not performed, as all the parents ($n = 79$) were included because the population was small and accessible.

Variables and measurements

The survey collected sociodemographic variables including age, sex, level of education, current occupation, the sex of the child diagnosed with ASD, comorbidities of the father/mother and level of parental stress. The latter variable was assessed using the parental stress questionnaire (PSI/SF, Parenting Stress Index, Short Form) [24,25]. This questionnaire was used to determine the level of stress experienced in the role of being a father or mother.

The PSI/SF has been used in research, confirming its reliability and validity [26]. Researchers Copeland and Lee Harbaugh (2005), in the United States, administered the PSI/SF to 74 first-time mothers aged between 18 and 41 years. The data analysis revealed a good internal consistency for the total scale (0.92). In addition, in the parent domain, Cronbach's alpha was 0.87, in dysfunctional

interaction 0.86, and in childcare stress 0.85 [27]. In Peru, Pineda Gonzales reported an internal consistency, based on Cronbach's alpha coefficient of 0.93 for the parental stress scale. Regarding the domains, the values were 0.84, 0.82 and 0.87 for parental distress, dysfunctional parent-child interaction and childcare stress, respectively [16]. On the other hand, the PSI shows good internal consistency (α = 90), as well as adequate test-retest reliability (r = 84) [28,29].

The PSI/SF is based on a 36-item questionnaire with a 5-point Likert scale and provides a final score that indicates the level of stress perceived by parents. This questionnaire is divided into three subscales. The first is called "parental distress" (questions 1 to 12), assesses the stress perceived by parents in their role as caregivers, and addresses their sense of competence, the limitations that caring their children imposes on various aspects of their life, in addition to their challenges with their partners and the lack of social support. The second is the "dysfunctional parent-child interaction" (questions 13 to 24), which assesses parents' expectations regarding their children's achievements. The third and last subscale is called "difficult child" (questions 25 to 36), which assesses parents' perception of managing their children's behavior [24].

The PSI/SF has a scoring range from 36 to 180 for the total score. A score above 90 indicates a clinically significant level of stress [30].

The survey was conducted both online and in person. The online completion was facilitated through the ARIE institution, which sent the survey to each selected parent via e-mail. On the other hand, physical surveys were distributed to parents who came to the institution in person, bringing their young children who received scheduled occupational therapy in 2022.

A total of 20 surveys were completed through an online form, and 59 surveys were filled out physically. All the surveys included an informed consent form explaining the study and detailing that it was anonymous to protect personal information.

Statistical analysis

A database was created using Microsoft Excel 2019 software, incorporating information from both the online form and the physical surveys. Subsequently, an analysis was performed using IBM SPSS Statistics, version 27. Qualitative variables were expressed as frequencies and percentages; quantitative variables were expressed as means and standard deviation. The parental stress score was the sum of the three subscales of the survey, and a score above 90 would indicate a clinically significant level of stress [30]. The bivariate analysis was conducted between parental stress and sex, level of education and type of family, considering a significance value of $p < 0.05$.

Ethical considerations

Approval for this study was obtained from the ethics committees of the School of Human Medicine at the Universidad de San Martín de Porres and the research department of the Instituto para el Desarrollo Infantil-ARIE prior to its implementation. The personal information of the patients was kept strictly confidential and anonymous throughout the study. Informed consent was implemented to explain the research topic and objectives to the parents, emphasizing that their participation was voluntary and involved no risk. In addition, the benefit of this study lies in providing relevant information that can serve as the foundation for providing guidance and support to parents in the management of challenges related to the disorder, thereby fostering an atmosphere of conversation and understanding among them.

RESULTS

A total of 79 parents met the inclusion criteria. The average age of the surveyed parents was 35.20 and the age range was 26 to 46 years. The most frequent group consisted of adult parents, accounting for 86.07 % (*n* = 68), followed by young parents, with 13.93 % (*n* = 11). Moreover, 31.64 % (*n* = 25) were male and 68.36 % (*n* = 54) were female. Of the 79 parents, single individuals predominated with 50.63 % (*n* = 40), while married individuals were 45.56 % (*n* = 36). Higher education was most predominant, accounting for 73.42 % (*n* = 58), followed by those with completed complete secondary education, with 26.58 % (*n* = 21). Finally, the majority of parents (44.32 %) lived in a family-owned home (Table 1).

Table 1. Sociodemographic characteristics of parents of children diagnosed with ASD at ARIE, SJL branch

Characteristics *N* = 79	*n*	%	Standard dev.	Mean
Sex of the parent				
Male	25	31.64		
Female	54	68.36		
Age			5.21	35.20
Young (18-29 years)	11	13.93		
Adult (30-59)	68	86.07		
Marital status				
Single	40	50.63		
Married	36	45.56		
Divorced	2	2.53		
Widow(er)	1	1.28		
Level of education				
Completed second. educ.	21	26.58		
Higher	58	73.42		
Occupation				
Lawyer	1	1.26		
Administrator	7	8.90		
Homemaker	28	35.44		
Student	2	2.53		
Geologist	1	1.26		
Self-employed	24	30.38		
Engineer	2	2.53		
Construction foreman	1	1.26		
Not specified	6	7.59		
Political scientist	1	1.26		
Healthcare professional	6	7.59		
Condition of the housing				
Owned	22	27.84		
Rented	22	27.84		
Family-owned	35	44.32		

Regarding parental stress, it is observed that 60 parents (including both fathers and mothers) exhibit clinically significant stress because their score on the survey was above 90 (Table 2).

Table 2. Levels of stress among parents of children diagnosed with ASD at ARIE, SJL branch, 2022

Parental stress *N* = 79	*n*	%
Normal range	19	24.05
Clinically significant	60	75.95

Regarding parental stress, the chi-square analysis found a significant association ($p < 0.05$) between the sex of the parent and clinically significant parental stress, with mothers having higher levels of stress, with 83.33 % ($n = 45$), compared to fathers, with 60 % ($n = 15$). A significant association ($p < 0.05$) was also found between parental stress and the sex of the child, with males producing higher parental stress, with 82.14 % ($n = 46$), compared to females, with 60.87 % ($n = 14$). An analysis of the parents' level of education found that those with a completed secondary education exhibit slightly higher levels of stress (76.20 %) compared to those with higher education (75.87 %). However, this difference is not statistically significant ($p > 0.05$). It was observed that 51.85 % ($n = 28$) of mothers, despite having a higher level of education, were not practicing their profession, possibly due to the pressures of caring for their children. Likewise, it was observed that 95.46 % ($n = 21$) of single-parent families presented a higher level of stress compared to 68.42 % ($n = 39$) of two-parent families, this result being significant ($p < 0.05$) (Table 3).

Table 3. Parental stress according to sociodemographic variables among parents of children diagnosed with ASD at ARIE, SJL branch, 2021

Variables *N* = 79	Mild parental stress *n* = 19		Clinically significant parental stress *n* = 60				$x^2(p)$
	n	%	*n*	%	*n*	%	
Sex of the parent							0.024
Male	10	40.00	15	60.00	25	100.00	
Female	9	16.66	45	83.33	54	100.00	
Sex of the child							0.044
Male	10	17.86	46	82.14	56	100.00	
Female	9	39.13	14	60.87	23	100.00	
Level of education							0.976
Secondary	5	23.80	16	76.20	21	100.00	
Higher	14	24.13	44	75.87	58	100.00	
Type of family							0.012
Two-parent family	18	31.58	39	64.42	57	100.00	
Single-parent family	1	4.54	21	95.46	22	100.00	

DISCUSSION

This study found that the majority of parents (75.95 %, $n = 60$) exhibit clinically significant stress. These results are consistent with the findings of Pineda Gonzales in a similar population at other ARIE branches: she found that the majority of parents (89.65 %) exhibited clinically significant stress [16]. However, it differs in terms of the distribution of stress between fathers and mothers. While Pineda Gonzales found higher levels of clinically significant stress among fathers (92.3 %), our study observed that mothers predominantly exhibited higher levels of stress (83.33 %). These differences could be attributed to the sample size and the location of the study [16].

The study by Bueno Hernandez et al. showed that 66.7 % of parents who were members of Aspau-Peru had stress, which is similar to our study, where we found that 75.95 % presented stress [15]. On the other hand, Pozo Cabanillas et al. found that 87 % of mothers exceeded the level of

PSI/SF > 90, considered clinically significant, which is very close to our findings, where 83.33 % of mothers presented clinically significant stress [30].

A possible explanation for why mothers present higher levels of stress compared to fathers may be that, despite having a higher level of education, 51.85 % (n = 28) of mothers are not practicing their profession due to the responsibilities and care required by their children with ASD. Bueno Hernández et al. found that 73.7 % of mothers had to resign from their jobs to care for their children with autism, since the demands of care are higher [15].

In another study, conducted by Ferreira and Najar on single parenthood and raising children with autism, four mothers in single-parent families were examined. They faced challenges due to the lack of a life partner and emotional support. These findings are reflected in our research, where a significant association (p < 0.05) was found between single parenthood and clinically significant stress in parents. Clinically significant stress was observed in 95.6 % of families where children live with one of their parents [31].

In summary, the results of this research have revealed that parents of children with ASD attending the Instituto de Desarrollo Infantil ARIE, SJL branch, experience elevated levels of stress. These findings are supported by the previously mentioned studies. The reason for this stress lies in the special care required by children diagnosed with ASD: the effects of this responsibility result in diverse levels of stress. It is important to note that if parents do not know how to properly manage this stress, it may cause detrimental consequences both for their own health and for the development of their children.

Therefore, it is recommended that institutions dedicated to the diagnosis and therapeutic treatment of patients with ASD develop strategies aimed at mitigating stress among parents of children with ASD. These strategies should include coping approaches that help parents deal with the challenges and issues in caring for their children. In this way, the emotional well-being of parents can be preserved, and appropriate responses can be provided to their specific needs.

Author contributions: KWPA designed the study, managed permissions, conducted data collection and the pertinent analyses, and wrote the manuscript, including its final version. LRPS participated in the study design, data analysis, writing of the article, and final drafting of the manuscript. All authors approved the final version and take responsibility for the content of the article.

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