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Research Article

Emotional Dysregulation and Parental Stress in ASD Patient

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Abstract

Introduction: Parents with children with neurodevelopmental disorders suffer chronic stress and are more susceptible to suffering mental and physical health problems.

Objective: To determine if the emotional dysregulation of patients with ASD are associated to the parental stress.

Materials and Methods: An observational analytical study of 47 children with primary ASD and symptoms of emotional dysregulation. The degree of parental stress was measured with a self-response questionnaire. Each child were clinically evaluated and was the following scales were used: ATEC scale, the Stress scale for parents of children with ASD (APSI) (online) and the Inventory of emotional symptoms (ISDE) created by authors (online).

Results: The parental stress measured by the APSI scale were associated with the ISDE in the moderate/severe grades (OR = 2.19, p = 0.019), especially in girls 6 years of age or older.

Conclusion: The major stressors for parents are the central symptoms of autism and expectations for the social future of their children. Must be taken care of and social efforts made for the future integration of children with ASD into our society.

Keywords: *Parental Stress; Autism; Emotional Dysregulation; ASD*

Abbreviations

ASD: Autism Spectrum Disorder; ATEC: Autism Treatment Evaluation Checklist; APSI: Autism Parenting Stress Index; CDC: Center for Disease Control; ED: Emotion Dysregulation; DSM-5: Diagnostic and Statistical Manual of Mental Disorder; Ed. 5. ISDE: Inventory of Symptoms of Dysregulation Emotion

Introduction

Autism spectrum disorders (ASD) include neurodevelopmental disorders with increasing prevalence in the last decade. During 2014, CDC reported in the US one of their highest prevalence 1.7, representing 1/59 children [1]. In Mexico reported a prevalence of 0.87%, 1/115 children [2]. ASD affects verbal and non-verbal communication, socialization, stereotyped conducts, the main symptoms in the DSM-5 manual of the American Psychiatric Association [3]. The etiology of ASD considered multifactorial shows a great phenotypic variability, especially with the expressive skill of language, psychiatric comorbidities, and other cognitive abilities. Its complete heterogeneity and phenotypic expression are still unknown [4]. Patients with ASD can develop emotional dysregulation, especially the high performance ASD, including behavioral outbursts, angry behavior and auto-aggression and aggressive behavior to others, destruction or throwing objects. This dysregulation generally produces emotional problems and disturbed social interaction in home and school. Patients with

emotional dysregulation have difficulties modulating the intensity or duration of the internal motivators that produce emotions and fail to adapt to social expectations [5]. Emotional dysregulation relates to ASD and other psychiatric or neurodevelopmental problems [6]. Some authors associate parental stress with emotional dysregulation in a day-to-day routine [7-9]. Parents rising their ASD children often face increased risk of stress related diseases, probably because the immunologic imbalance due chronic hipocortisolism [10,11]. Our research question was: parents with ASD children that present social dysregulation develop more stress?

Objective of the Study

The objective of this paper is to determine if the emotional dysregulation of patients with ASD are associated to the parental stress.

Materials and Methods

The present study was prospective, transversal, and analytic. We recruited the population sample from seven private neurologic therapy centers of the city. We invited 164 children already diagnosed with ASD during January 2019. All parents of the patients signed an informed consent form, and the study was approved by the "Comité de Ética e Investigación del Hospital Regional Materno Infantil de los Servicios de Salud de Nuevo León, México" (DEISC-PR-190119006).

All patient included were received a neurologic evaluation and the ASD diagnosis were confirmed according with the Diagnostic and Statistical Manual of Mental Disorder (DSM-5) [12] and the Autism Treatment Evaluation Checklist (ATEC) [13]. Each participant had a clinical history with emphasis in neurologic pathologies, neurologic sequels, or genetic syndromes. Parents of each child returned to investigators the Autism Parenting Stress Index (APSI) [14] and the Inventory of Symptoms of Dysregulation (ISDE) (online) created by the authors. Only those who with all the evaluations were included in the analysis the materials and methods that are used to complete the study should be mentioned.

Study Scales

We selected the ATEC scale to determine the symptomatic grade of autism. The scale measures language and communication skills, sociability, sensorial and cognitive conscience, physical health, and behavior. The score is graded as mild (20 - 49 points), moderate (50 - 79 points) and severe (≥ 80 points) [15,16]. The APSI scale (online) was selected to determine the level of parental stress while caring autistic children. The scale measures central symptoms of autism, comorbid behaviors, and comorbid physical problems. Items were answered with a five-points Likert scale: 1) do no stress me, 2) sometimes stress me, 3) stress me often, 4) stress me daily, 5) stress me so much, I cannot handle any more [14]. The ISDE (online) was designed by authors to determine the symptoms of emotion dysregulation (ED). The scale measure emotional symptoms, each with their respective intensity with a 5-points Likert scale: 1) Very low, almost never occurs. 2) Low, it occurs sometimes, but do not generate mayor problem 3) Moderate, it occurs half the time and generate problem 4) Intense, it occurs more than half the time and generate much problem 5) Very intense, it occurs all the time and produces much problem. For the statistical analysis, we used statistical software IBM SPSS® Ver. 18, and STATA Ver. 15 (College Station, TX). For the continuous variables with normal distribution, we used t-Student test and correlation, for categorical variables we used Chi square test, Kolmogorov-Smirnov test. For quality assurance of the test, we used Cronbach's alpha test. We accepted an alpha error of 0.05.

Results and Discussion

Only 47 completed the initial neurologic evaluation and tree tests and were included in the analysis (Figure). The rate boy/girl was 3.7, and the mean age ± standard deviation in girls was 7.8 ± 2.4 (range 3.9 - 11.3) and in boys was 6.6 ± 2.5 (range 3.3 - 12.7), with no significant difference ($p = 0.366$). If age is grouped 20 (46.6%) were younger than 6 years old (< 6y) and 27 (57.5%) were 6 years or older (≥ 6y). 36% of patients were first born, 43% second child, 17% third child, and 43% forth child. The mean value for ATEC, APSI, ISDE do not varied significantly according to the number of children in family ($p = 0.268$, $p = 0.417$, $p = 0.989$, respectively). Figure 1 shows the density distribution of the ATEC scale of boys and girls, with no statistical difference using Kolmogorov-Smirnov test (boys $p = 0.986$, girls $p = 0.309$). In addition, the density distribution of the ATEC scale by age groups, with higher scores in the (≥ 6y) ($p = 0.011$). Table 1 shows that most of the respondents (55.7%) had a combined low to moderate scores of ISDE. If we examine each scale level, there were two spikes one in the moderate score (44.7%) and the other in the severe level (40.4%). The single item more named was anxiety crisis, followed by high pain threshold and involuntary laugh. The Cronbach's alpha of the ISDE scale was 0.80.

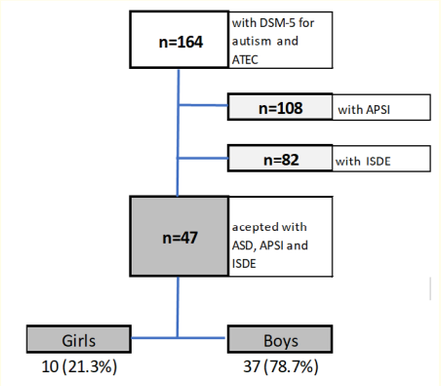

Figure: *Patient flowchart.*

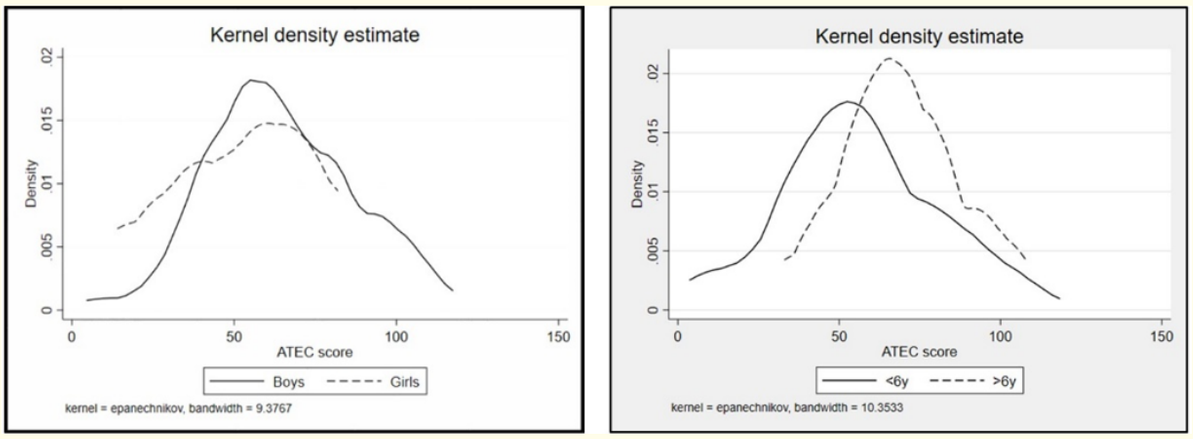

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Figure 1: *Kernel density distribution by ATEC and gender and age group.*

Variable	Total (mean± SD)	Light (mean ± SD)	Moderate (mean ± SD)	Severe (mean ± SD)	Very Severe (mean ± SD)	Mean interinal covariance	Cronsbach alpha
Anxiety crisis	2.36 ± 1.19	0.8 ± 0.84	2.05 ± 0.92	2.95 ± 1.03	4.00 ± 0.00	0.38	0.77
Rage crisis	1.43 ± 1.23	0.4 ± 0.55	0.76 ± 0.70	2.26 ± 1.19	3.00 ± 0.00	0.36	0.76
Fear crisis	1.15 ± 0.86	0.8 ± 0.84	1.14 ± 0.85	1.16 ± 0.83	2.00 ± 1.41	0.47	0.81
Autoagression	0.87 ± 1.03	0.4 ± 0.55	0.48 ± 0.51	1.42 ± 1.35	1.00 ± 0.00	0.43	0.79
Heteroagression	0.74 ± 1.09	0.4 ± 0.55	0.48 ± 0.51	1.11 ± 1.56	1.00 ± 0.00	0.39	0.78
Involuntary laughing	1.83 ± 1.29	0.6 ± 0.55	1.67 ± 1.06	2.11 ± 1.33	4.00 ± 1.41	0.37	0.77
Involuntary crying	1.13 ± 0.90	0.4 ± 0.55	0.86 ± 0.73	1.53 ± 0.90	2.00 ± 1.41	0.42	0.78
High threshold to pain	1.94 ± 1.45	1.0 ± 1.41	1.57 ± 1.33	2.53 ± 1.39	2.50 ± 2.12	0.37	0.78
Low threshold to pain	0.81 ± 1.04	0.8 ± 0.84	0.90 ± 1.26	0.68 ± 0.89	1.00 ± 0.00	0.44	0.80
Total (mean and %)	2.38 ± 0.74	5 (11%)	21 (44.7%)	19 (40.4%)	2 (4.3%)	0.40	0.80

Table 1: *Symptoms distribution by ISDE.*

Table 2 in the APSI scale the lower and casual levels of stress was present in 36% and the frequent and intense level in 64% of respondents. The more sensible questions causing more stress were the preoccupation for the future independent life of their children, their future social acceptance, the sphincters control issues, and not feeling attach to their children. The Cronbach's alpha was 0.83. Table 3 shows the scores of ATEC, APSI and ISDE by gender. In the ATEC scale, the severe grade was most common in boys (22%) compared with girls (10%). In the ISDE scale the severe grade also predominate in boys (43%) compared with girls (30%), the intense level were present only in two boys (5%). In the APSI scale, the higher levels of stress were found in girl´s parents (20%) compared with boys (3%). The ISDE

scores were higher in > 6y (p = 0.014). Table 4 shows the ATEC, APSI and ISDE by range of age. Younger children showed higher mean ATEC scores compared with > 6y, (68.8 and 56.6 points, respectively, p = 0.187). Moderate DE was most common in > 6y (59%) compared with < 6y (15%). APSI level 4, stress me level was more common in < 6y (20% compared with > 6y (7%). Figure 2 shows higher APSI scores in girls > 6y compared with girls < 6y (3.7 and 2.7, respectively p = 0.033). The APSI scores do not vary in boys (p = 0.171). APSI and ISDE results were associated in their moderate and severe levels (p = 0.067) in girls and (p = 0.001) in boys. Figure 3 shows that a ISDE score moderate-sever produce a higher risk for parental stress (OR = 2.19, p = 0.019), in both boys and girls. Table 5 shows the individual items of ISDE. Anxiety crises were correlated with moderate-severe levels of APSI scores 0.35 (p = 0.005), an inversely proportional to the pain threshold -0.40 (p = 0.018).

Variable	Obs	Total (mean ±DS)	Std. Dev.	No stress (mean ± DS)	Sometimes stress me (mean ± DS)	Often stress me (mean ± DS)	Stress me daily (mean ± DS)	Stress me so much I can´t stand it (mean ± DS)	Mean Internal Covariance	Cronsbach´s alpha
Social Development	47	1.81	0.92	2 ± 1.41	1.00 ± 0.53	2.08 ± 0.86	2.36 ± 0.84	2.00 ± 0.00	0.29	0.82
Communication abilities	47	1.81	1.21	1.5 ± 2.12	1.07 ± 0.70	1.92 ± 1.04	2.14 ± 1.29	3.67 ± 0.58	0.27	0.82
Tantrums	47	1.21	0.95	0.5 ± 0.71	0.87 ± 0.52	1.38 ± 1.04	1.50 ± 1.22	1.33 ± 0.58	0.29	0.82
Heteroagression	47	0.53	0.95	0 ± 0.00	0.27 ± 0.46	0.54 ± 0.88	0.86 ± 1.41	0.67 ± 0.58	0.28	0.82
Autoagression	47	0.34	0.73	0 ± 0.00	0.13 ± 0.52	0.31 ± 0.63	0.50 ± 0.94	1.00 ± 1.00	0.31	0.83
Dificulty in changing activities	47	0.79	0.88	0.5 ± 0.71	0.47 ± 0.64	0.92 ± 0.86	1.00 ± 1.18	1.00 ± 0.00	0.29	0.82
Sleeping problems	47	0.79	1.00	0.5 ± 0.71	0.60 ± 0.83	0.69 ± 0.86	0.86 ± 1.10	2.00 ± 1.73	0.29	0.82
Diet or Alimentary problems	47	1.04	1.00	1.5 ± 0.71	1.00 ± 1.13	1.00 ± 0.91	0.93 ± 1.07	1.67 ± 0.58	0.31	0.84
Intestinal problems	47	0.70	1.04	1.5 ± 2.12	0.53 ± 0.99	0.54 ± 0.66	0.64 ± 1.15	2.00 ± 1.00	0.29	0.83
Sphincter control problems	47	0.91	1.40	1.5 ± 2.12	0.87 ± 1.30	0.77 ± 1.36	0.64 ± 1.15	2.67 ± 2.31	0.28	0.83
You do not feel close to your child	47	1.21	1.16	1.5 ± 0.71	0.80 ± 1.01	1.23 ± 1.17	1.36 ± 1.28	2.33 ± 1.15	0.28	0.82
Future aceptance of your child	47	2.28	0.95	2 ± 1.41	1.67 ± 0.82	2.31 ± 0.86	2.79 ± 0.89	3.00 ± 0.00	0.28	0.82
Independent life of your child	47	2.32	0.84	2 ± 1.41	1.73 ± 0.70	2.31 ± 0.75	2.86 ± 0.66	3.00 ± 0.00	0.28	0.82
Total (mean and %)	47	3.02	1.03	2 (4%)	15 (32%)	13 (28%)	14 (30%)	3 (6%)	0.29	0.83

Table 2: *Symptom distribution by APSI (n = 47).*

	Boys		Girs		Total		
Degree of Autism	**Frequency**	**(%)**	**Frequency**	**(%)**	**Frequency**	**(%)**	**(p)***
Light	9	24	4	40	13	28	0.528
Moderate	20	54	5	50	25	53	
Severe	8	22	1	10	9	19	
ISDE							
Very light	3	8	2	20	5	11	0.571
Light	16	43	5	50	21	45	
Moderate	16	43	3	30	19	40	
Intense	2	5	0		2	4	
APSI							
No stress	2	5	0	0	2	4	0.341
Sometimes stress me	12	32	3	30	15	32	
Often stress me	11	30	2	20	13	28	
Stress me daily	11	30	3	30	14	30	
Stress me so much I cant stand it	1	3	2	20	3	6	

Table 3: *Scale results of ATEC, APSI and ISDE by gender (n = 47).*

**Chi square. APSI= Autism Parenting Stress Index; ISDE=Inventory of Symptoms of Dysregulation.*

	Age 6 years or less			Age > 6 years	Total		
Degree of Autism	**Frequency**	**(%)**		**Frequency**	**(%)**	**Frequency**	**(p)***
Light	2	10	11	41	13	28	0.065
Moderate	13	65	12	44	25	53	
Severe	5	25	4	9	9	19	
ISDE							
Very light	4	20	1	4	5	11	0.016
Light	12	60	9	33	21	45	
Moderate	3	15	16	59	19	40	
Intense	1	5	1	4	2	4	
APSI							
No stress	10	10	7	26	17	36	0.317
Sometimes stress me	8	40	8	30	16	34	
Often stress me	5	25	10	37	15	32	
Stress me daily	4	20	2	7	6	13	

Table 4: *Scale results of ATEC, APSI and ISDE by age groups (n = 47).*

**Chi square. APSI= Autism Parenting Stress Index; ISDE=Inventory of Symptoms of Dysregulation.*

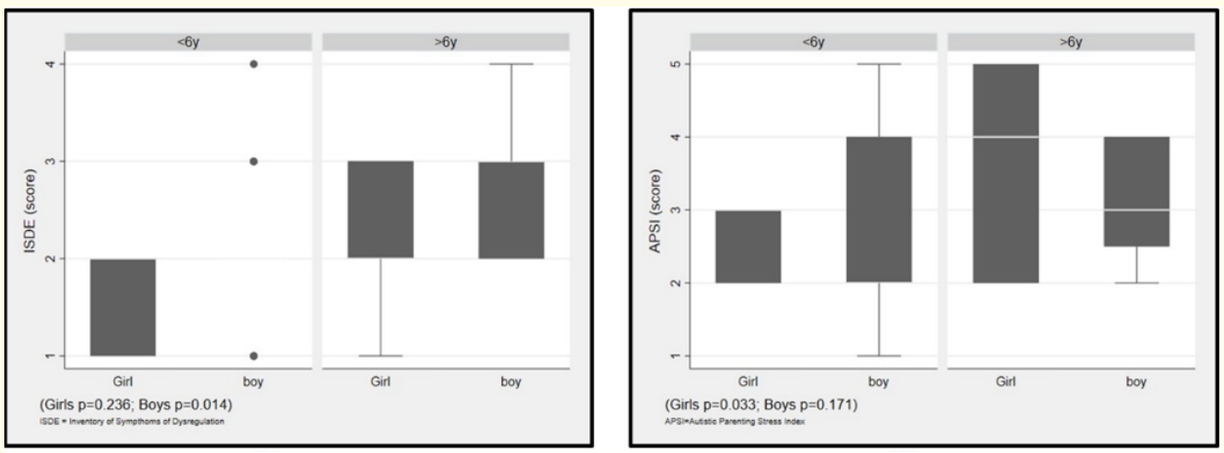

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Figure 2: *ISDE and APSI score distribution by age groups.*

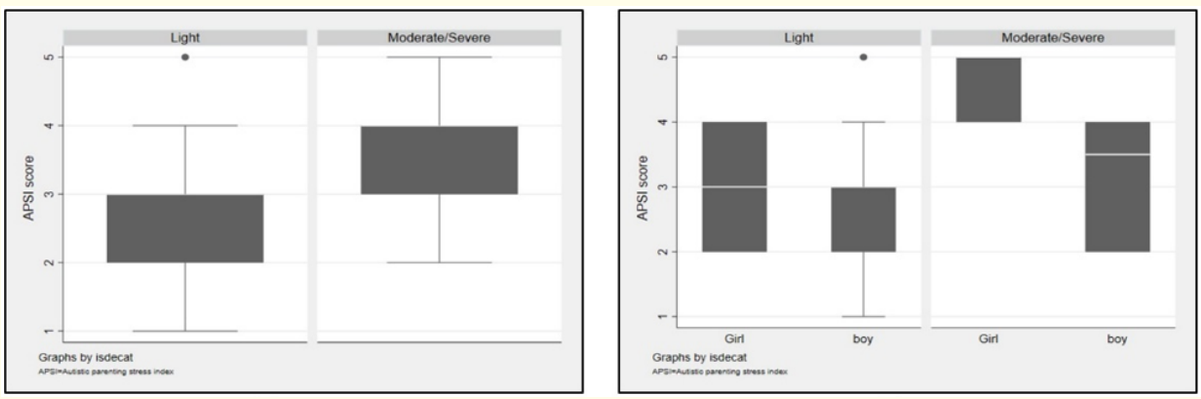

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Figure 3: *APSI score distribution by light and moderate/severe grades of ISDE.*

Variable	Correlation	(p)
Anxiety crisis	0.42	0.003
Low threshold to pain	-0.36	0.012
Involuntary crying	0.23	0.118
Autoagression	0.23	0.126
Rage crisis	0.18	0.223
Fear crisis	-0.18	0.239
Heteroagression	0.16	0.285
High threshold to pain	0.04	0.767
Involunatary laughing	-0.03	0.842

Table 5: *Pearson´s correlation of moderate and severe Symptoms of DE and APSI (n = 47).*

Parental stress is the individual reaction of one of the children´s parents while parenting. It is multifactorial because it can be related to the children characteristic, the parent characteristics, the spouse characteristics, and the father-mother/child bondage type [17]. In this paper, our approach was more clinical, centered in the patient symptomatology, not in the parental psychologic aspects, nor the parents-child relationship. Comorbidity more commonly reported in children with are abnormal sensorial responses (90%), sleep interruptions (86%), gastrointestinal symptoms (70%), self-aggressive behavior (34%) and aggressively /irritability (22%) [18-21]. The central symptoms of autism and comorbidities can affect almost all aspects of the child functions. This represents a big challenge to the parental skills and might affect their mental health [22]. Our results also found that sensorial alterations as rage crisis is associated with self and other´s aggression.

Parenting itself can produce stress, having or not autistic children. Parenting is a dynamic process that commonly starts before conception, with many of parental expectations on their children´s future and lasts permanently all the vital cycle [23].

This expectative factor to their children´s future is one of the higher stressors, surpassing behavioral or conduct problems. Mothers receive the bigger load of stress or direct caretakers of these children as confirmed in many other studies [24-26]. Some mothers add to the normal home care duties of their children and active participation in therapeutic programs, in specialized centers but also in their own homes. These extra duties, self-imposed can easily overload the mother try to keep up the therapeutic goals for the development of their children with ASD [27].

Conclusion

We found that the better predictors for parental stress of parents with children with ASD are the low expectation for their children to have future opportunities of an independent and integrated life and the social skills deficits. The anxiety crisis of these children was associated to parental stress, probably because their capacity to physically control them, especially if they are bigger and stronger. Another parental stressor is the low pain threshold because they need to be permanently alert to avoid permanent damage and lesions. The present study explores the ED and the parental stress and there a very few studies in this topic nationally. We need to work more with the parental expectative, fears, frustrations, and myths. We need to give them alternatives for social adaptation and future care of their children and to promote the social inclusion of their children in our community. The limitation of our study is the small size of the sample and that we are using a non-validated ISDE scale.

Conflict of Interest

None of the authors has any conflict of interests.

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