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Correlation between verbal communication of children with autism spectrum disorders and the level stress of their parents

Correlação entre a oralidade de crianças com distúrbios do espectro do autismo e o nível de estresse de seus pais

Leticia Segeren¹, Fernanda Dreux Miranda Fernandes¹

ABSTRACT

Purpose: To assess the stress levels of parents of children with autism and to verify its association with the inability of verbal communication. **Methods:** Participated in this study the parents of 175 children who were divided into three groups (parents of children with ASD without verbal communication, parents of children with ASD with verbal communication and parents with no complaints about their children development) and responded to the stress level questionnaire. **Results:** Most parents from the three groups presented medium level of stress and that there was no significant difference between parents of children with autism with or without verbal communication. When parents of children with autism were compared with parents from the control group a significant difference was observed, with more parents of children with autism showing high levels of stress. **Conclusion:** The stress level on parents of children with autism not influenced by their lack of verbal communication.

Keywords: Autistic disorder; Parents; Language; Nonverbal communication; Stress, Psychological

RESUMO

Objetivo: Investigar o nível de estresse de pais de crianças com autismo, verificando sua associação com a ausência de oralidade na comunicação de seus filhos. **Métodos:** Participaram pais de 175 crianças, que foram divididos em três grupos (pais de crianças com DEA com e sem comunicação verbal e pais de crianças sem queixas no desenvolvimento) e responderam ao questionário de nível de estresse. **Resultados:** A maioria dos pais dos três grupos apresentou médio nível de estresse e não houve diferença significativa entre os pais de crianças com autismo, com e sem comunicação verbal. Quando os pais de crianças com autismo foram comparados aos pais do grupo controle, foi verificada diferença significativa. **Conclusão:** O nível de estresse de pais de crianças com autismo não é influenciado pela ausência de oralidade na comunicação de seus filhos.

Descritores: Transtorno autístico; Pais; Linguagem; Comunicação não verbal; Estresse psicológico

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INTRODUCTION

The Autism Spectrum Disorders (ASD) are characterized as a behavioral syndrome that affects the developmental process throughout the life. There is great variability in number and severity of symptoms in the areas that define the diagnosis^(1,2). According to the diagnostic criteria proposed by the DSM-5 (American Psychiatric Association - APA)⁽³⁾, it is possible to identify the first symptoms before the 36th month of life.

The DSM-5⁽³⁾ states that the ASD are characterized by pervasive deficits in the areas of communication and socialization, with restrict and repetitive behavioral patterns, interests and activities.

The identification of a condition, disorder or impairment on a child impacts the lives of the whole family, specially the parents'. Moreover, the diagnosis of autism is frequently informed to the family on a generic and superficial way, with emphasis on the information about the child's developmental disorders, along with other incomplete and subjective impressions^(4,5) generating a strong emotional response by the parents, such as shock, sadness, despair and confusion⁽⁶⁾.

The impact on each family member varies individually but all are affected by it, with feelings of loss and grief, demanding careful consideration about how the parents cope with the situation and relate with their child⁽⁶⁾.

The important role of parents in the child's development and intervention processes has been pointed out as essential by studies conducted in the last few years. However a literature review indicated that the number of studies about parents' participation is smaller than was expected^(1,7,8).

There is also a lack of scientific publications based on results of academic research, which limits the outreach of the knowledge generated by recent research in the field⁽⁹⁾.

The difficulties posed by the routine care of persons with autism, it is also necessary to focus the attention on the caretakers because they also demand a special care. The caretaker also needs assistance to cope with the every-day challenges associated with the child's difficulties⁽¹⁰⁾.

Brazilian researchers conducted a study about orientation to mothers of children with ASD, aiming to assess the interference of systematic mentoring sessions of with specific themes, during a short period of time⁽¹¹⁾. The authors concluded that these orientations improved the child's communicative environment and also to the family's understanding about the child's abilities and inabilities.

The parental stress in a family with a child with ASD is considerably higher than in families without a child with ASD or with children with other impairments⁽¹²⁾. That is, parents of children with ASD experience different aversive stimulus or subjective, behavioral and physiological responses⁽¹³⁾.

It also shows the clear need for early familiar support with assistance to parents aiming to decrease the overload and improving the family's health and coping processes^(12,14).

Communication is an area specially affected in children with ASD and can be a factor in increasing the parent's stress since it is one of their first concerns. The impairments in this area lead to difficulties in communicating with other children and adults with great variations from child to child⁽¹⁵⁾.

Therefore, this study proposes the question if the lack of oral communication in children with ASD increases the stress level of their parents. This way, we aimed to verify the association of the stress level identified in parents of children with ASD is associated with their child's oral communication abilities.

METHODS

The research and its consent form was approved by the research ethics board of the School of Medicine, *Universidade de São Paulo* (USP) with the protocol # 185/13.

Participants were 175 parents of children with ASD divided in three groups:

- G1: parents of 33 children with ASD that describe their child as non-verbal;
- G2: parents of 42 children with ASD that describe their child as verbal;
- G3: parents of 100 children without complaints about their child development.

Inclusion criteria

Children should have a medical diagnosis of ASD and be enrolled in speech-language therapy to be included in G1 or G2.

Participants were divided between G1 and G2 according to the parents' impressions about their communication (whether they presented speech or not). In the beginning of the questionnaire about stress answered by the parents of children with ASD there was a question regarding communication. The participants were asked if they thought their child presented speech or not, that is, if their child could communicate verbally. This was the distribution criteria between groups G1 and G2.

Parents of the control group (G3) shouldn't have any complaints about their child development. Therefore, in the beginning of the questionnaire was included a question asking if the participant had any complaint about the development of their child, that should have age between 6 and 7 years.

Age wasn't considered an inclusion criteria for the research groups (G1 and G2), allowing the participation of the parents of all children receiving speech-language therapy in the service. Alternatively, an specific age-range was

determined for the control group, aiming to focus on a group with balanced development, when the first milestones of early development were already over and there are still none of the unsettling elements of adolescence.

Exclusion criteria

Participants that didn't answer the questionnaire, didn't sign the consent form, presented two answers to one question, didn't answer any of the questions or had any other relation to the child besides than parenthood were excluded from the study. Besides that, in the control group, those who answered positively to the question regarding the child's development were excluded from the research.

Procedures

To the research groups, direct contact was made with the parents and the questionnaire was answered during an interview. All participants of these groups signed the approved consent form and answered questions regarding social-demographic information besides those about stress level (Appendix 1).

To the parents of the control group, the questionnaires were sent, along with explanatory letter. The answer to the questionnaire within one week was considered acceptance to participate in the research.

G3 was comprised by parents of children that went to four different regular schools: one private and one public school of the city of Sao Paulo and one private and one public school of a small country city. This way we aimed to reach different social economic groups, with different social demographic characteristics, determining a heterogeneous group.

Material

The questionnaire about the stress level had 39 objective questions divided in three domains: 1 - Family (13 questions); 2 - Physical symptoms (12 questions) and 3 - Communication with the child (14 questions). The formulation of questions of domains 1 and 2 aimed to use simple language that could be understood by the parents, therefore minimizing the need for additional clarifying. Questions of the third domain were extracted from a questionnaire about the communicative difficulties perceived by the parents of children with ASD that is routinely used in the service where this study was conducted⁽⁷⁾. This way, besides identifying the areas with more stress, it was possible to associate these data with the communicative difficulties between the parents and their child.

The scoring system of the questionnaire was determined for each question, where the score 3 (three) was attributed to the answer "always"; the answer "frequently" scored 2

(two); the answer "rarely" received score 1 (one), and "never" scored 0 (zero).

The scores were added and the sums of the scores of all questions were classified as: "no apparent stress" when the sum was bellow 20; "medium level of stress" when the total score was between 21 and 46, and "high level of stress" when the total score was equal or over 47.

RESULTS

Social demographic data

The analysis of data indicated that the mean age of the participants of the research groups (G1 and G2) was 38 years – varying between 23 and 58 years – while in the control group (G3) the mean age was 34 – varying between 22 and 60 years. That is, the age mean and range was similar in the three groups.

The same was true regarding the number of children for each participant, where the mean for all groups was 2 children, varying between 1 and 4 children.

Although in all the groups most of the participants declared being married, this proportion was larger in the research groups. If the participants that declared being "on a stable relationship" were added to the married ones, it would include 78% of the participants of the research groups and 64% of the control group.

It was possible to observe that, although the control group was not paired to the research groups, education level was also similar in all the groups. Most of the participants have completed the 12th grade.

Stress level

The 175 participants were classified according to the score in the stress level questionnaire.

Analysis of the stress level of parents with children with ASD (G1 and G2)

Considering all the 75 parents of children with ASD, 33 of G1 and 42 of G2 were considered, the majority presented medium level of stress.

Analyzing the two groups separately with the Likelihood Ratio Test, there were no differences in the selected variables.

Mann-Whitney test was used to verify differences between the groups G1 and G2 and the scores of the stress level of each domain (Table 1).

This analysis indicates that there were differences between groups just the domain "Family". There were no differences between the groups regarding the other domains or the total score.

Analysis of the stress level of parents with no complaints about the development of their children with ASD (G3)

When the control group (G3) was analyzed separately there were few participants with no apparent stress (17%) or with high level of stress (17%), that is, 66% of the participants of the control group presented medium level of stress.

Parents of children from four different schools comprised this group. Therefore, we analyzed if there were any differences in the stress level of the participants that were associated with the different schools.

The Likelihood Ratio Test aiming to verify the differences associated to different schools is synthesized in Tables 2 and 3.

There was no significant difference in the total score of stress level of the participants. However, when considering the domains, it could be noted that parents whose children went to a private school in Sao Paulo had higher scores in

the domain “Family” and lower scores in the third domain, associated of the child’s communication difficulties.

Comparing the stress level of parents with children with ASD (G1 and G2) and parents without complains regarding their child’s development (G3)

The significance level of $p < 0.001$ was obtained when comparing the stress level of parents of the research groups and of the control group (Table 4).

The group of parents with children with ASD had more participants with high level of stress (41.3%), while in the control group this proportion was 17%.

The Mann-Whitney test identified differences between participants of the research groups (G1 and G2) and those of the control group (G3) (Table 5).

The stress level of the parents of children with ASD was higher than that of parents without complaints about their

Table 1. Stress level scalar variables on G1 and G2

Variable	Group	n	Mean	Standard deviation	Minimum	Maximum	Percentile 25	Percentile 50 (Mediana)	Percentile 75	p-value
SL – total points	G1	33	44.21	15.4	18	77	31.5	42	58	0.505
	G2	42	46.69	15.8	21	79	32	46	58	
	Total	75	45.6	15.57	18	79	32	45	57.5	
SL – dom. 1 – Family	G1	33	13.7	5.5	4	25	10	14	17.5	0.029*
	G2	42	16.81	5.51	7	28	13	17	20.5	
	Total	75	15.44	5.69	4	28	11	15	20	
SL – dom. 2 – Physical symptoms	G1	33	14.09	7.49	3	34	8.5	12	20	0.806
	G2	42	14.29	7.51	1	30	9	13	21	
	Total	75	14.2	7.45	1	34	9	13	20.25	
SL – dom. 3 – Child	G1	33	16.42	5.56	7	27	12	16	21	0.649
	G2	42	15.6	6.41	3	28	10.5	16	21	
	Total	75	15.96	6.02	3	28	11	16	21	

*Significant values ($p < 0.050$) – Mann-Whitney Test

Subtittle: SL = stress level; dom. = domain; G1 = parents of children with ASD that describe their child as non-verbal; G2 = parents of children with ASD that describe their child as verbal

Table 2. Stress level on G3, analyzed separately by school type

Category	Group								p-value
	Priv. Sch. SP		Pub. Sch. SP		Priv. Sch. Aguaí		Pub. Sch. Atibaia		
	Freq.	Perc.	Freq.	Perc.	Freq.	Perc.	Freq.	Perc.	
No apparent stress	1	5	6	20	6	30	4	13.3	0.059
Medium level of stress	19	95	17	56.7	11	55	19	63.3	
High level of stress	0	0	7	23.3	3	15	7	23.3	

*Significant values ($p < 0.050$) - Likelihood Ratio Test

Subtittle: Priv. Sch. = private school; Pub. Sch. = public school; Freq. = frequency; Perc. = percentage

Table 3. Stress level scalar variables on G3

Variable	Group	n	Mean	Standard deviation	Minimum	Maximum	Percentile 25	Percentile 50 (Mediana)	Percentile 75	p-value
SL – total points	Priv. Sch. SP	20	31.1	9.01	14	47	23.25	30.5	36	0.388
	Pub. Sch. SP	30	35.83	16.27	7	87	24.5	32.5	46.50	
	Priv. Sch. Aguaí	20	30	14.19	7	57	16.5	29.5	42.75	
	Pub. Sch. Atibaia	30	35.8	13.13	9	60	23.75	38	46.50	
	Total	100	33.71	13.75	7	87	23	32	44.75	
SL – dom. 1 – Family	Priv. Sch. SP	20	13.1	3.97	6	20	11	13.5	15.75	0.162
	Pub. Sch. SP	30	12.4	6.15	2	27	8	10	17.50	
	Priv. Sch. Aguaí	20	9.6	5.16	2	21	4.5	10.5	13	
	Pub. Sch. Atibaia	30	11.1	5.22	2	20	7	10	15.25	
	Total	100	11.59	5.36	2	27	8	11	15	
SL – dom. 2 – Physical symptoms	Priv. Sch. SP	20	11.5	5.26	3	23	8	10.5	14.75	0.397
	Pub. Sch. SP	30	13.03	6.74	1	30	8.75	12	17	
	Priv. Sch. Aguaí	20	10.15	6.35	2	25	4.25	10.5	13	
	Pub. Sch. Atibaia	30	12.9	7.12	0	28	7	12.5	17.25	
	Total	100	12.11	6.52	0	30	7	11.5	16	
SL – dom. 3 – Child	Priv. Sch. SP	20	6.5	2.95	2	15	5	6	8	0.001*
	Pub. Sch. SP	30	10.4	6.83	1	30	4.75	8.5	16.25	
	Priv. Sch. Aguaí	20	10.25	5.01	3	24	6	10.5	13	
	Pub. Sch. Atibaia	30	11.8	4.42	3	24	8.75	11	15	
	Total	100	10.01	5.42	1	30	6	9	13	

*Significant values (p<0.050) – Kruskal-Wallis test

Subtitle: SL = Stress level; dom. = domain; Priv. Sch. = private school; Pub. Sch. = public school

Table 4. Stress level on parents of children with ASD (G1+ G2) and control group (G3)

Category	Groups				p-value
	G1 + G2		G3		
	Freq.	Perc.	Freq.	Perc.	
No apparent stress	1	1.3	15	15.	<0.001*
Medium level of stress	43	57.3	68	68.	
High level of stress	31	41.3	17	17.	

*Significant values (p<0.050) - Likelihood Ratio Test

Subtitle: G1 = parents of children with ASD that describe their child as non-verbal; G2 = parents of children with ASD that describe their child as verbal; G3 = control group; Freq. = frequency; Perc. = percentage; ASD = Autism Spectrum Disorders

child development. This different was not significant jut for the domain “physical”.

DISCUSSION

In what refer to the marital status, there was a difference between the participants of this study – where 71% declared to be married - and a research conducted in a country town of the state of Sao Paulo⁽⁵⁾ where just 33% of the participants declared the same status.

Analyzing also the characterization of the participants of this study, the educational level was similar in all the groups, where most of the participants have completed the 12th grade^(5,16).

Those studies and another one conducted in Australia⁽¹⁷⁾ show that a large part of the participants quit working to stay at home and take care of the child with ASD. It was also observed in the participants of G1 and G2 of this research, where 55% of the children’s caretakers reported to be house wives, without any paid employment or day-job.

Table 5. Stress level scalar variables on parents of children with ASD (G1+ G2) and control group (G3)

Variable	Grup	n	Mean	Standard deviation	Mínimum	Maximum	Percentile 25	Percentile 50 (Mediana)	Percentile 75	p-value
SL – total points	G1+G2	75	45.6	15.57	18	79	32	45	57.5	<0.001*
	G3	100	33.71	13.75	7	87	23	32	44.75	
	Total	175	38.81	15.67	7	87	28	36	49	
SL – dom. 1 – Family	G1+G2	75	15.44	5.69	4	28	11	15	20	<0.001*
	G3	100	11.59	5.36	2	27	8	11	15	
	Total	175	13.24	5.81	2	28	9	13	18	
SL – dom. 2 – Physical symptom	G1+G2	75	14.20	7.45	1	34	9	13	20.25	0.084
	G3	100	12.11	6.52	0	30	7	11.5	16	
	Total	175	13.01	6.99	0	34	8	12	18	
SL – dom. 3 – Child	G1+G2	75	15.96	6.02	3	28	11	16	21	<0.001*
	G3	100	10.01	5.42	1	30	6	9	13	
	Total	175	12.56	6.39	1	30	8	11	17	

*Significant values ($p < 0.050$) – Mann-Whitney Test

Subtitle: SL = stress level; dom. = domain; G1 = parents of children with ASD that describe their child as non-verbal; G2 = parents of children with ASD that describe their child as verbal; G3 = control group; ASD = Autism Spectrum Disorders

The literature review⁽¹⁸⁾ about stress, autism and family shows that the communication issue was approached with focus on the disorders, without association with the parents' stress.

A study with 62 mothers⁽¹⁹⁾ of children with ASD suggested that the main factor of stress is associated with having a child with ASD and not to any specific factor.

The present research suggests that the parents of verbal children with ASD (G2) and parents of children with ASD that do not speak do not have different levels of stress. In both groups the majority of the participants presented medium level of stress. These results agree with a prior research⁽²⁰⁾ that concluded that the verbal ability doesn't have any influence in the parents' stress level.

A research with 101 mothers and 23 fathers of children with ASD from two cities of Australia⁽²¹⁾, aiming to identify their major source of stress didn't associate it to the children communication level. The main focus of stress of the mothers was associated to the children's social difficulties while to the fathers sensorial and cognitive issues generated most of the stress.

This way, when focusing on the participants with high level of stress it was noted that the proportion was larger in G2 than in G1 and it is the opposite to what was observed in Greece⁽²²⁾, that is, mothers of verbal children with ASD presented a lower level of stress than mothers of non-verbal children with ASD. These authors suggest that the main cause of stress of the mothers was their child's behavior and personality.

Several studies indicate that parents of children with ASD face difficulties in the relationships within the family.

However these difficulties were not associated to the communicative level of the children^(5,23,24).

Comparing the stress level of parents of children with ASD (G1 and G2) and parents of the control group (G3) it was possible to identify a significant difference between them. The research groups (G1 and G2) has a larger proportion of participants with high level of stress (41.3%) while the control group (G3) had a less proportion of participants with high stress level (17%) and more participants with apparent no stress.

These data agree with several other studies that state that parents of children with autism have more stress than parents without complaints about their children development or than parents of children with other conditions, such as Down syndrome^(12,18,25).

The hypothesis that parents of children with ASD have higher levels of stress than parents of children with typical development was confirmed also by another study⁽²⁰⁾. The authors couldn't associate the stress levels to variables such as age of the child, communication ability or severity of the symptoms.

CONCLUSION

Most of the parents of children with ASD presented a medium level of stress, as well as parents without complaints about their child development.

Even with similar levels of stress, significantly more parents of children with ASD have high level of stress.

The main limitations of this study refer to the difficulties in

associating level of stress to the number of children, parent's educational level and social economic level, due to the number of subjects with ASD, that didn't allow the determination of relevant subgroups of analysis.

It can be concluded that the level of stress of the parents of children with ASD doesn't seem to be associated the lack of speech. However, a higher level of stress was observed in the parents of children with ASD, therefore supporting the notion that there should be more attention focused in the well being of the parents of children with ASD.

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Appendix 1. Questionnaire

Name: _____

Age: _____ Date of birth: _____ Marital Status: _____

Profession: _____ Education: _____

Number of children: _____

Does your child speaks? () Yes () No

Please, answer to the questionnaire with the most appropriate option regarding your family and your feelings

Stress level questionnaire		Never	Almost never	Almost always	Always
1	Do you argue at home (with spouse or other family members)?				
2	Does your love life is disappointing?				
3	Does your child gets upset when witnesses a familiar argument?				
4	Are there familiar disputes about how much to spend and where?				
5	Do you feel that at home there is not enough dialogue, you don't listen to each other enough?				
6	Do you feel that the persons that live in your home are angry with each other?				
7	Do you feel that the home tasks are too much work for you?				
8	Do you feel there is not enough time to do everything you must do?				
9	Do you argue with your spouse or other family members about who should do what with your child?				
10	Are there things you consider impossible to do with your child?				
11	Are you called at school to talk about your child's behavior?				
12	At home, do you talk about your feelings?				
13	Do you know what is important to your child?				
14	Do you feel there is not enough money to the important things?				
15	Do you feel there is some tension between the persons that live in your house?				
16	Does your child reaches your expectations at school?				
17	How often do people that live in your house have their meals separately?				
18	Do you feel your muscles, jaws or neck are tense??				
19	Do you have heartburns without apparent cause?				
20	Do you forget things in your frequently?				
21	Do you feel you are too irritable?				
22	Do you feel as "disappearing", leaving everything out?				
23	Do you have the feeling you will not be able to cope with everything that is happening?				
24	Do you have recurrent thoughts or talk to people about the same subject?				
25	Are you too anxious?				
26	Do you have sleeping disorder (sleep too much or too little)?				
27	Do you feel you are already tired when you wake-up?				
28	Do you think you could do everything better?				
29	Do you have the feeling that nothing is really worth it ?				
30	Do you know what to do with your child's general behavior?				
31	Do you have difficulties to communicate with your child?				
32	Do you have difficulties to play with your child?				
33	Can you understand what your child feels?				
34	Do you have the feeling your child do not understand what you say?				
35	Do you feel that people avoid your child?				
36	Do you like to go to public places with your child?				
37	Do you get upset because your child do not initiate communication?				
38	Do you get upset with your child's apathy or agitation?				
39	Do you have difficulties teaching new things to your child?				