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Prevalence of anxiety and depression in parents of children with autism spectrum disorder during the first wave of the COVID-19 pandemic on Northeast Brazil

Prevalência de ansiedade e depressão em pais de crianças com transtorno do espectro autista durante a primeira onda da pandemia de COVID-19 no Nordeste do Brasil

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ABSTRACT

Objective: Estimate the prevalence of anxiety and depression symptoms in parents of children with autism spectrum disorder (ASD) during the first wave of the Coronavirus Disease (COVID-19) pandemic, comparing them with parents of neurotypical children and with other mental disorders. **Methods:** Responses from 211 participants were collected from an online form about familial behavior during the pandemic, and the Portuguese version of the HADS scale (Hospital Anxiety and Depression Scale). **Results:** Anxiety symptoms were present in 51% of the sample and depression was present in 35.1%. The prevalence of depression and anxiety symptoms was 58% and 44.4% respectively in the group of parents of children from the ASD; 50.3% e 32.2% for parents of neurotypical children; and 40% and 35% in the group of parents of children with other mental disorders. **Conclusions:** The prevalence of anxiety and depression in parents during the pandemic was greater than that of before the pandemic period. The prevalence of anxiety symptoms, as well as the mean scores of anxiety and depression symptoms, were significantly higher for the group of parents of children with the ASD. The results point to the need for additional care for parents and caregivers of children with ASD, since the social isolation adopted as a measure to contain the pandemic seemed to pose as a risk factor for negative psychological effects especially in this group.

KEYWORDS

Parents, mental health, autism spectrum disorder, COVID-19 pandemic.

RESUMO

Objetivo: Estimar a prevalência de sintomas de ansiedade e depressão em pais de crianças com transtorno do espectro autista (TEA), durante a primeira onda da pandemia da doença causada pelo coronavírus SARS-CoV-2 (COVID-19), comparando com pais de crianças típicas e com outros transtornos mentais. **Métodos:** Foram coletadas respostas de 211 participantes a partir de um questionário *on-line* sobre comportamento familiar durante a pandemia e da versão em português da escala HADS (*Hospital Anxiety and Depression Scale*). **Resultados:** Sintomas de ansiedade estiveram presentes em 51% da amostra e de depressão, em 35,1%. A prevalência de sintomas de ansiedade e depressão foi de 58% e 44,4%, respectivamente, no grupo de pais de crianças com TEA, 50,3% e 32,2% no grupo de pais de crianças típicas e 40% e 35% no grupo de pais de crianças com outros transtornos mentais. **Conclusões:** As prevalências de ansiedade e depressão em pais durante a quarentena foram superiores àquelas fora do período pandêmico. As prevalências de sintomas de ansiedade, bem como as médias dos escores de sintomas de ansiedade e depressão, foram maiores no grupo de pais de crianças com TEA. Os resultados indicam a necessidade de atenção aos pais e cuidadores das crianças com TEA, já que o isolamento social adotado como medida de contenção da pandemia se constituiu como um fator de risco para impactos psicológicos negativos especialmente nesse grupo.

PALAVRAS-CHAVE

Pais, saúde mental, transtorno do espectro autista, pandemia de COVID-19.

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INTRODUCTION

In December of 2019, cases of pneumonia associated with severe acute respiratory syndrome (SARS) were first reported in China, specifically at the Hubei province and Wuhan city. The Coronavirus Disease (COVID-19) is caused by a new coronavirus, denominated SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2) by the World Health Organization (WHO). Due to its high transmissibility, COVID-19 rapidly spread throughout Europe and to the rest of the world, causing the WHO to declare the outbreak a pandemic on March 11, 2020[1,2]. At this moment, there are over 430 million confirmed cases of COVID-19 and around 6 million deaths around the world. In Brazil, there are almost 29 million cases and over 640 thousand confirmed deaths[3]. Currently, new variants of the virus have been causing new challenges to the health systems, scientific community, governments, and the entire population.

In many countries, social distancing measurements were implemented to prevent infections from spreading among people (*e.g.*, closure of schools, universities, retails, companies, and public establishments)[4]. Consequently, many individuals had their routines significantly altered and needed to adapt to a new reality, in which families needed to stay at home for longer periods, with new dynamics for work, study, leisure and domestic activities and children and/or elderly care. Under this perspective, the quarantine scenario due to COVID-19 has become a new likely risk factor for negative psychological effects on the general population, like fear, anxiety, anguish, stress, loneliness, and depression[4,5]. The economic impact, the social distancing, the deprivation of outdoor activities, the risk of getting infected with the virus and the excess of media coverage and information are a few potential factors that can be associated with those symptoms.

People who got COVID-19 and their family members, healthcare professionals, the elderly, those with underlying medical conditions, children, and their respective caregivers, are groups that tend to be more psychologically affected and demand special attention[2]. Parents of people with autism already present with an elevated prevalence of anxiety and depression symptoms[6,7], especially when their children present more severe behavioral symptoms[8], thus being a more vulnerable population to psychological distress during the pandemic.

This study's objective is to estimate the prevalence of anxiety and depression symptoms among parents of children with ASD, making a comparison with parents of neurotypical children and with other mental disorders, on Northeast Brazil, during the first wave of the COVID-19 pandemic.

METHODS

The subjects were recruited through the research authors social media platforms to answer an online form, aiming for a "snowball effect". The main researchers coordinated an academic research and clinical care group that targeted the autism spectrum disorder (ASD). The answers were obtained during the first wave of COVID-19, between August and September of 2020.

The online form consisted of questions that involved the collection of sociodemographic data, family structure, behavior during the pandemic, and can be defined as a Brazilian version of the HADS scale (Hospital Anxiety and Depression Scale) to evaluate symptoms of anxiety and depression on parents and a Brazilian version of the WHOQOL-Bref to evaluate quality of life[9,10]. Those who scored 8 or greater on their respective sub-scales were considered positive for anxiety and depression, according to the HADS scale standardization for Brazil[9]. The forms were inserted into the RedCap Platform from the Bahiana School of Medicine and Public Health. The data corresponding to anxiety and depression symptoms will be presented in this article, and the data referring to quality of life will be published separately.

The online form answers were converted to data to the IBM SPSS (Statistical Packaged for Social Science) software v.20, for Windows, in which the statistical analysis of the data was performed. The chi-square test was carried out to evaluate the distribution of variables on the three parent groups: parents of children with ASD, parents of children with other mental disorders (OMD) or epilepsy and parents of children with no referred mental disorders (NMD).

The research project was approved by the Ethics in Research Committee of the *Fundação Bahiana para o Desenvolvimento das Ciências* on July 22, 2020, filed under the CAAE 31492720.1.0000.5544 number. The participants agreed to the Informed Consent Form (ICF). Upon clicking the link, the participant was redirected to the ICF, which contained information on the study, its risks and guaranteed the confidentiality of the information provided.

RESULTS

There were 306 attempts to access the forms, from which 211 valid answers were identified. Regarding the sociodemographic data, 86.2% of the forms were completed by women and 13.8% by men. The majority of participants were between 40 and 50 years of age (51.7%) and referred to be married or in a common-law marriage (78.2%). As for schooling, 93.8% were either enrolled or had completed graduation

or post-graduation. The study had the contribution of parents that lived in different regions of Brazil, 75.8% lived in the capital of their respective state; 87.6% lived at Northeast Brazil, from which the majority resides at the state of Bahia. Concerning religion, 71.1% of the participants stated that they belong to a religion. Relating to work, 39.3% were self-employed, 54.5% were formally employed and 6.2% were unemployed. The monthly earnings of 75% of those who answered the form is 1300 to 3900 USD, over 3900 USD for 28% and less than 260 USD for 2.8%. The Table 1 arranges sociodemographic data, stating that between the three groups of parents there was only a significative difference regarding the place of residence, due to the fact that all individuals from the OMD group resided on their state's capital.

Table 1. Sociodemographic characteristics

Variable	NMD		ASD		OMD		p
	n	%	n	%	n	%	
Gender							
Female	124	85.5	39	86.7	18	90.0	**0.857**
Male	21	14.5	6	13.3	2	10.0	
Age							
23 to 39 years old	41	29.5	12	27.3	3	16.7	**0.687**
40 to 50 years old	69	49.6	25	56.8	10	55.6	
Over 50 years old	29	20.9	7	15.9	5	27.8	
Marital status							
Has a partner	114	78.1	36	80.0	15	75.0	**0.902**
Does not have a partner	32	21.9	9	20.0	5	25.0	
Schooling							
High school	9	6.2	4	9.1	0	0	**0.376**
Higher education	137	93.8	40	90.9	20	100	
City that lives in							
Capital	112	76.7	28	62.2	20	100	**0.004***
Not a capital	34	23.3	17	37.8	0	0	
Religious							
Yes	104	71.2	32	71.1	14	70.0	**0.994**
No	42	28.8	13	28.9	6	30.0	
Work							
Self-employed	56	38.4	18	40.0	9	45.0	**0.212**
Formal	84	57.5	21	46.7	10	50.0	
Unemployed	6	4.1	6	13.3	1	5.0	
Family income							
Over 1,300 dollars a month**	108	74.0	27	60.0	16	80.0	**0.131**
Less than 1300 dollars a month**	38	26.0	18	40.0	4	20.0	
Number of people living at the house							
1 to 3	67	46.2	19	42.2	5	25.0	**0.178**
4 or more	78	53.8	26	57.8	15	75.0	
Number of rooms at the house							
1 to 3	103	70.5	34	75.6	11	57.9	**0.863**
4 or more	43	29.5	11	24.4	8	42.1	
Number of bathrooms at the house							
1 to 3	100	69.0	37	82.2	12	60.0	**0.124**
4 or more	45	31.0	8	17.8	8	40.0	

NMD: group of parents of children with no referred mental disorders; ASD: group of parents of children with autism spectrum disorder; OMD: group of parents of children with other mental disorders.
*$p < 0.05$
**R$ 1,045.00 was considered the current monthly minimum wage in Brazil according to Provisional Measure nº 919, from January 30, 2020 and the U.S. dollar value at the time was around R$ 4.00.

Concerning the children's characteristics/traits/attributes, parents referred that 146 (69%) did not suffer from any mental disorder and 65 (31%) had any mental disorder, 45 (21.33%) of which had ASD and 20 (9.48%) had other mental disorders or epilepsy. The results will be presented comparing the variables between the three groups: no referred mental disorders (NMD), ASD and other mental disorders (OMD). Regarding activities and habits during the pandemic, the Table 2 indicates that the parents from the ASD group remained at home for significantly more shifts and received less help with household activities. There were no significant differences among the other groups concerning the other variables.

Table 3 indicates that the use of psychotropic medication by the parents and children was significantly more frequent in the ASD and OMD groups and the presence of mental disorders on parents was also significantly more prevalent in both these groups in comparison to NMD. The alcoholic beverage consumption during the pandemic was significantly less prevalent on the ASD group and more prevalent in the OMD group. There was no difference between the groups regarding illicit drug use and smoking.

The prevalence of anxiety and depression symptoms were 51% and 35% respectively from the total sample: 58% and 44.4% on ASD group; 50.3% and 32.2% in OMD group, thus there was not a significant statistical difference among the groups (Table 4).

Table 2. Activities and habits during the pandemic

Variable	NMD		ASD		OMD		p
	n	%	n	%	n	%	
Social distancing							
Yes	135	92.5	40	88.9	19	95.0	**0.646**
No	11	7.5	5	11.1	1	5.0	
Shifts in which stays at home							
3 shifts	91	62.3	35	79.6	8	40.0	**0.005***
2 shifts	29	19.9	3	6.8	3	15.0	
1 shift	26	17.8	6	13.6	9	45.0	
Weekly frequency in which leaves the house							
Every day or almost every day	37	25.3	9	20.5	5	25.0	**0.479**
1 to 3 times	99	67.8	29	65.9	15	75.0	
Never	10	6.9	6	13.6	0	0.0	
Weekly frequency in which watches or reads the news							
Every day or almost every day	61	41.8	27	60.0	10	52.6	**0.356**
1 to 3 times	72	49.3	16	35.6	9	47.4	
Never	13	8.9	2	4.4	0	0.0	
Receiving workers at home							
Yes	59	40.7	13	28.9	9	45.0	**0.301**
No	86	59.3	32	71.1	11	55.0	
Having friends or family over							
Yes	27	18.6	5	11.1	4	20.0	**0.475**
No	118	81.4	40	88.9	16	80.0	
Public transportation user							
Yes	8	5.6	3	6.7	0	0.0	**0.519**
No	136	94.4	42	93.3	20	100.0	
Someone helps with household activities							
Yes	106	73.6	21	47.7	14	70.0	**0.006***
No	38	26.4	23	52.3	6	30.0	

NMD: group of parents of children with no referred mental disorders; ASD: group of parents of children with autism spectrum disorder; OMD: group of parents of children with other mental disorders.
*$p < 0.05$

Table 3. Parents' emotional characteristics during the pandemic

Variable	NMD		ASD		OMD		p
	n	%	n	%	n	%	
Anxiety							
HAD-A Score > 8	73	50.3	26	57.8	8	40.0	**0.402**
Depression							
HAD-A Score > 8	47	32.2	20	44.4	7	35	**0.322**
Smoking							
Yes	8	5.5	2	4.4	0	0.0	**0.554**
No	138	94.5	43	95.6	20	100.0	
Alcohol drinking							
Yes	96	65.8	15	33.3	16	80.0	**0.000***
No	50	34.2	30	66.7	4	20.0	
Illicit drug user							
Yes	3	2,1	0	0,0	0	0	**0.508**
No	143	97.9	45	100.0	20	100.0	
Participant using psychotropic medication							
Yes	13	8.9	12	26.7	5	25.0	**0.004***
No	133	91.1	33	73.3	15	75.0	
Children using psychotropic medication							
Yes	0	0.0	30	66.7	12	63.2	**0.000***
No	146	100.0	15	33.3	7	36.8	
Participant has a mental illness							
Yes	18	12.3	12	27.3	5	25.0	**0.038***
No	128	87.7	32	72.7	15	75.0	

NMD: group of parents of children with no referred mental disorders; ASD: group of parents of children with autism spectrum disorder; OMD: group of parents of children with other mental disorders.
*$p < 0.05$

Table 4. Anxiety and depression median score

Instruments	Factors	Groups			Kruskal- Wallis
		NMD n = 146	ASD n = 45	OMD n = 20	p-value
Median Score M(SD)	Anxiety	7.455 (3.799)	8,067 (3.353)	7.600 (3.347)	0.558
	Depression	6.171 (3.655)	7.756 (3.821)	6.600 (2.703)	0.049*

NMD: group of parents of children with no referred mental disorders; ASD: group of parents of children with autism spectrum disorder; OMD: group of parents of children with other mental disorders.
*$p < 0.05$

DISCUSSION

Evaluating the sample as a whole, the prevalence of anxiety and depression symptoms found among the parents was 51.0% and 35.1% respectively. Estimates prior to the pandemic indicated that about 5.8% Brazilians had a positive diagnose for depression and 9.3% for anxiety[11]. After the emergence of COVID-19, a study done with 45.161 Brazilians estimated a 52.6% prevalence of anxiety or nervousness symptoms and 40.4% of depression or sadness[12], uncover similar data to those found in this study sample. In a meta-analysis performed with studies from European countries and Asia estimated that the prevalence of anxiety symptoms was 32%, and 34% for depression during the first wave of the pandemic. It is possible that the pandemic's impact on mental health produces long-lasting challenges to the public health[13], indicating that the health services should prepare to meet this demand.

The prevalence of anxiety symptoms, as well as the mean scores for anxiety symptoms, were greater for the ASD parent group (58% for ASD, 50% for NMD and 40% for OMD), however, the different was not statistically significant regarding the other groups, probably due to the sample size.

The prevalence of symptoms of depression was also greater on the ASD group, but the difference was not statistically significant (44% for ASD, 32% for NMD and 35% for OMD); yet the mean scores for depression wore significantly higher on the ASD group. Studies performed prior to the pandemic had already suggested an elevated prevalence of anxiety and depression symptoms on parents of children with ASD in Brazil[8], and in other countries[14,15]. Some studies done during the pandemic's first wave also indicated a higher prevalence of anxiety and depression on parents of children with other disorders and parents of neurotypical children. A study done in China estimated higher anxiety scores for parents of ASD children in comparison with parents of children with other disorders, but the difference between the groups also was not statistically significant, similarly to what's being presented on this current study[16]. In China, a study comparing parents of children with ASD and parents of children with a typical development, pointed out significantly higher anxiety and depression scores on the group of parents of ASD children[17]. A study carried out in Portugal also indicated that parents of children with ASD had higher anxiety levels than parents of children who had a typical development[18].

The results showed that the ASD group was significantly more exposed to environmental stressors; remained at home for longer periods of time and received less assistance on household tasks. Social distancing and the reference to lack of social support are environmental stressors that were already a part of ASD families before the pandemic[19]. On the other hand, the economic impact, the social distancing, the deprivation of outdoor activities, the risk of getting infected with the virus and the excess of media coverage and information are just a few potential factors that have been generating or aggravating symptoms such as anxiety, stress, fear, anger, guild, anguish, insomnia, feelings of loneliness and/or being trapped and depression in society[2]. Studies performed outside the pandemic period already pointed out that symptoms of anxiety and depression in parents of ASD children were associated to their behavioral issues in children and less social support[8,20], what is possibly being exacerbated due to the extended isolation periods demanded by quarantine and lockdown[4]. A study conducted during the first wave of the pandemic demonstrated that parents of ASD children report greater behavioral changes in their children and a greater difficulty to manage emotions, which can be a contributing factor to a higher risk of adaptive emotional symptoms in this group of parents[18].

The findings demonstrate that the ASD and OMD groups had significantly more mental disorders, and both parents and children used more psychotropic drugs than the group of neurotypical children. These results were anticipated, as the literature before the pandemic documents that parents of ASD children are at a greater risk to develop a mental disorder and need to use psychotropic drugs[21]. A Chinese study done during the first wave of the pandemic revealed that parents of ASD children are more susceptible to mental health disorders when compared to parents of children with other disorders, due to changes in child's behavior, dysfunctional relationship between parent and children, as well as parental psychological demands and lack of friends, family, and professional support[22]. Furthermore, the importance of providing greater care for the psychological vulnerabilities of parents of ASD children, as a population, lies in the higher negative impact on the ASD children, in the event of their condition and loss of capability to meet the everyday needs and demands of their children[8,20].

Although both ASD and OMD groups are more susceptible to mental disorders and both take more psychotropic medication, the consumption of alcoholic beverages is significantly less prominent in parents of ASD children and higher in those with children with other mental disorders. It is possible that in the OMD group, alcoholism and other conditions associated with it are more prevalent, justifying the higher rates of alcoholic beverages consumption in the OMD group. However, that does not justify the lower rates in the ASD group. It can be assumed that the demand to care for ASD children is so intense during the pandemic, leaving less time for individual recreational activities, like the social consumption of alcoholic beverages.

The sociodemographic data reveals that this sample does not reflect the Brazilian population as a whole, because it represents a subpopulation of people with higher incomes and levels of education. This bias is due to the fact that the form was shared mostly between people belonging to upper social classes.

The limitations of this study involve the online form method, using a self-assessment questionnaire with premade responses, where neither the parents nor the children were evaluated by healthcare professionals. Furthermore, the study does not reflect the global population of Brazil, due to the sample's high socioeconomical level. It can be assumed that for the Northeast Brazil population with lower schooling and socioeconomic levels, the symptoms are even more intense, due to supplemental challenges to those present in this sample.

CONCLUSIONS

This study shows how parents of individuals with mental disorders, especially autism spectrum disorder, are suffering

greater impacts on mental health during the pandemic when compared to the general population. These results are expected at critical historical moments that challenge the inevitable limitations of these clinical conditions, although more specific data is needed. In this way, we understand that a multisectoral organization of care between health professionals, companies, organizations and society is necessary to minimize the consequences of this period.

INDIVIDUAL CONTRIBUTIONS

Milena Pereira Pondé – Contributed substantially to the design of the study, collaborated as guiding professor in data analysis and manuscript writing, and performed a critical review of this work.

Aracelles Alvarenga Medrado – Collected, organized, analyzed and performed the interpretation of the data, and contributed with large part of the manuscript writing.

Amanda Motta Silva – Helped in the organization the data and manuscript writing and translated the article into English.

Rafael Cabral Campos – Organized interviews on the RedCap system and helped in database formatting and data analysis.

Gustavo Marcelino Siquara – Contributed as guiding professor in database cleanup and data analysis and performed a critical review of this work.

CONFLICTS OF INTEREST

The authors declare no conflict of interest.

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