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The impact of the COVID-19 pandemic on children and adolescents with autism spectrum disorder and their caregivers

O impacto da pandemia de COVID-19 em crianças e adolescentes com transtorno do espectro autista e seus cuidadores

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ABSTRACT

Objective: To analyze the impact of the COVID-19 pandemic and social distancing on children and adolescents with autism spectrum disorder (ASD) and their caregivers. **Methods:** Observational, descriptive, and cross-sectional study conducted with parents/caregivers of children with ASD through an online questionnaire with 39 questions. Data were collected from October 2020 to January 2021, referring to the critical period of the pandemic in Ceará, from March to June 2020. **Results:** Of the 122 research participants (children/adolescents aged 2 to 18 years, average of 6.7 years), 87.7% interrupted multidisciplinary treatments during isolation. Most caregivers (86.8%) had more difficulties managing the children's free time. Behavioral problems became more intense for 61.5% and more frequent for 59.8% of participants. Difficulties in managing meals were reported by 39.3% of participants, and 97.1% stated that problems in managing autonomy were amplified. Behavioral regressions and worsening symptoms occurred in 81.1% of cases. Children and adolescents with pre-pandemic behavioral problems showed a significantly greater increase in the intensity (OR = 3.87, $p = 0.05$) and frequency (OR = 3.42, $p = 0.05$) of behavioral problems. In contrast, being an only child proved to be a protective factor against the negative impacts of isolation, with a significant reduction in the intensification (OR = 0.16, $p < 0.05$) and frequency (OR = 0.08, $p < 0.01$) of behavioral problems. Conclusion: The COVID-19 pandemic and social distancing negatively altered behavior, eating, and self-care patterns in children and adolescents with ASD, making this period more challenging for their caregivers.

Keywords: COVID-19; pandemic; autism spectrum disorder; caregivers; children; adolescents.

RESUMO

Objetivo: analisar o impacto da pandemia de COVID-19 e do distanciamento social em crianças e adolescentes com transtorno do espectro autista (TEA) e seus cuidadores. **Métodos:** estudo observacional, descritivo e transversal realizado com pais/cuidadores de crianças com TEA através de um questionário on-line com 39 questões. Os dados foram coletados de outubro de 2020 a janeiro de 2021, referindo-se ao período crítico da pandemia no Ceará de março a junho de 2020. **Resultados:** dos 122 participantes da pesquisa (crianças/adolescentes de 2 a 18 anos, média de 6,7 anos), 87,7% interromperam tratamentos multidisciplinares durante o isolamento. A maioria dos cuidadores (86,8%) teve mais dificuldades em gerenciar o tempo livre das crianças. Problemas de comportamento tornaram-se mais intensos para 61,5% e mais frequentes para 59,8% dos participantes. Dificuldades no manejo das refeições foram relatadas por 39,3% dos participantes, e 97,1% afirmaram que problemas na gestão da autonomia foram amplificados. Regressões comportamentais e piora dos sintomas ocorreram em 81,1% dos casos. Crianças com problemas de comportamento pré-pandemia apresentaram um aumento significativamente maior na intensidade (OR = 3,87, $p = 0{,}05$) e na frequência (OR = 3,42, $p = 0{,}05$) dos problemas comportamentais. Em contraste, ser filho único mostrou-se um fator protetor

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contra os impactos negativos do isolamento, com redução significativa na intensificação (OR = 0,16, p < 0,05) e na frequência (OR = 0,08, p < 0,01) dos problemas comportamentais. **Conclusão:** a pandemia de COVID-19 e o distanciamento social alteraram negativamente os padrões de comportamento, alimentação e autocuidado em crianças e adolescentes com TEA, tornando esse período mais desafiador para seus cuidadores.

Palavras-chave: COVID-19; pandemia; transtorno do espectro autista; cuidadores; crianças; adolescentes.

INTRODUCTION

The consequences of the COVID-19 pandemic and strict isolation have the potential to negatively affect people with autism spectrum disorder (ASD) and their families.[1] Children and young people with ASD are vulnerable to the effects of prolonged isolation or quarantine and may have difficulties adjusting to this new norm, especially since inflexibility and insistence on maintaining routines are hallmarks of ASD.[2]

In addition, a study shows that ASD may be a risk factor for respiratory disease caused by SARS-CoV-2, due to comorbidities that usually intensify the inflammatory system.[3] Parents, in turn, are also at risk of developing COVID-19.

Complying with prolonged social distancing measures and the fear of being infected by a highly infectious virus, whose origin, management and treatment are still unknown, can cause psychological distress in parents of children with ASD, as well as in children themselves, triggering a variety of short-term psychopathological symptoms, such as: stress, depressed mood, irritability, anxiety, fear, anger, insomnia and others; and long-term symptoms, such as: increased risk of alcohol abuse, binge eating, post-traumatic stress and depression.[4]

People with ASD and their family members are often represented by physical and emotional overload, loneliness, stress, depression and family instability.[5] It is possible that the isolation period and social distancing during the COVID-19 pandemic have created even more challenges for these families, mainly due to the break in routine, which, for autism, is a very important issue. However, each person and each family are a specific case, with their own context, possibilities, resources and variables; there is no general rule.

In this sense, the aim of this study was to analyze the impact of the COVID-19 pandemic and social distancing on children and adolescents with ASD and their caregivers in two important regions of the State of Ceará, specifically related to the first wave of the pandemic, in the period from March to June 2020.

METHODS

Study design

This is a cross-sectional, observational, exploratory, and descriptive study carried out with parents or caregivers of children and adolescents with ASD throughout Ceará. Data were collected from October 2020 to January 2021, and the information is related to the most critical period of the COVID-19 pandemic in 2020, from two regions of Ceará (Metropolitan Region of Fortaleza and Cariri Region) which corresponds to the months from February to June. Due to the social distancing measures imposed to reduce the transmission of COVID-19, the collection took place remotely through a questionnaire prepared on the Google® platform, called Google Forms, which was shared with the participants through a hyperlink. The research was posted on GENIT group Instagram profile, @genit_neurociencia, so that interested parties could request the link to the form. The associations of family members of autistic people in Ceará were also contacted through telephone and email so that they could help in the dissemination of the research. In this way, potential participants contacted the researcher by email or through WhatsApp® and were sent the questionnaire link.

Study population

The sample was taken for convenience, according to the interest and availability of parents or carers in answering the online questionnaire. The sample consisted of 122 parents or caregivers of children and adolescents of both sexes with an ASD diagnosis, regardless of the severity of the disorder. The ASD diagnosis was self-declared by those responsible.

Exclusion criteria were: uncertain diagnosis and diagnosis confirmed after the COVID-19 pandemic. Questionnaires whose participants did not meet the inclusion criteria or questionnaires partially completed without completion were excluded. All questions in the questionnaire were marked as mandatory, so the database consisted only of fully answered questionnaires.

Data collection instruments

The questionnaire was based on the instrument of Colizzi et al. (2020),[6] but was adapted to the Brazilian reality, dispensing full translation for cultural issues. Recognizing the importance of formal validation, a pilot test with 3 participants was conducted to assess the clarity of the questions, and the suggestions obtained were incorporated into the final questionnaire. The study questionnaire consists of 39 questions to be answered objectively (yes-or-no questions), in addition to multiple choice questions, including the collection of sociodemographic data related to the family, in addition to requesting information regarding the diagnosis, schooling and treatment of the child and issues that cover the main situations faced in the routine of children with ASD before and during the pandemic, from the perspective of parents/caregivers. The estimated time to answer the questionnaire was 20 minutes on average.

Data analysis

All responses were organized in Excel spreadsheets, Microsoft Office®, for descriptive statistical analysis (percentage). The results were grouped into categories, presented through tables and the discussions were supported by the scientific literature.

The analysis of the data was done by the calculation of frequencies and by multiple logistic regression. The dependent variables were intensity and frequency of behavioral problems during the period of social isolation due to the first wave of the pandemic of COVID-19, in the perspective of the parents or carers, the independent included characteristics of the child and the family and adversities experienced during the pandemic.

For logistic regression, the following variables were selected:

(I) age;
(II) be the only child (yes/no);
(III) parental status (married or living together/separated or single parent);
(IV) language (fluent/non-fluent);
(V) use of sleeping medications or behavioral problems (yes/no);
(VI) pre-emergency behavioral problems (yes/no);
(VII) support for multi-professional therapeutic services (yes/no);
(VIII) direct school support (yes/no);
(IX) intensity of behavioral problems after the outbreak of COVID-19 (more intense or less/equally intense);
(X) frequency of behavioral problems after the outbreak of COVID-19 (more intense or less/equally intense).

Ethical aspects

This study was submitted to the Research Ethics Committee through Plataforma Brasil, and approved under number 4.383.057, and followed all the ethical guidelines of Resolution nº 466, of December 12, 2012, of the National Health Council. The informed consent form (ICF) was sent online, on the front page of the questionnaire. Those who agreed to participate electronically signed it.

RESULTS

A total of 122 questionnaires completed by caregivers of children with ASD were analyzed. Table 1 describes the sociodemographic and clinical characteristics of children and adolescents with ASD during the COVID-19 pandemic in Ceará. According to the results, the average age of the study participants was 6.6 years (±3.67), and the majority of them were in the age group up to 10 years (82%), with a decreasing distribution as age increases.

The majority of participants lived in the metropolitan region of Fortaleza (61.2%), followed by the Cariri region (26.2%), and the vast majority resided in urban areas (91%). Most of the parents were living together (73.8%). In terms of financial conditions, it was noted that 45.9% had a monthly income of up to three minimum wages.

Another fact that attracts attention is the fact that approximately 40% of mothers had to leave home for work, this may have had implications in the direct support of the child with ASD during periods of social distancing. During the COVID-19 pandemic 30.3% of mothers and 28.7% of parents went to work at home (home office), (Table 1).

According to the participants, 41.8% of the child or adolescent with ASD was a single child. Among families with more than one child, 17.2% having more than a child diagnosed with any neurodevelopmental disorder, including autism.

With regard to language, about 43% of children speak few words or do not speak, while only 17% had fluent language. The presence of comorbidities may indicate the need for additional care and possibly greater vulnerability during the pandemic, however, it was by only 18.85% of participants.

About half of the young people (49.2%) were on pharmacological treatment for behavioral or sleep problems, highlighting the complexity of the symptoms associated with ASD and the need for multiple interventions. The majority of children (65.6%) were enrolled in private schools, and received therapy predominantly through health plans (57.4%) or privately (41.8%), (Table 1).

Table 1. Description of the sociodemographic and clinical characteristics of children and adolescents with ASD during the COVID-19 pandemic, Ceará, 2020/2021.

Age	**N**	**%**
≤ 5 years	55	45.08%
6 to 10 years	40	32.79%
9 to 15 years	21	17.21%
≥ 15 years	6	4.92%
Regions of Ceará State		
Metropolitan Region of Fortaleza	75	61.47%
Cariri Region	32	26.23%
Other	15	12.30%
Location of residence		
Rural area	11	9.02%
Urban area	111	90.98%
Parental Couple Status		
Married or cohabiting	90	73.8%
Separate or single-parente	32	26,2%
Monthly family income		
Up to a minimum wage	32	26.2%
From one to three minimum wages	24	19.7%
From four to 10 minimum wages	47	38.5%
More than 10 minimum wages	19	15.6%
Mother's employment situation during the critical period of the COVID-19 pandemic		
Commuting regularly to work	28	22.9%
Working from home	38	30.3%
Not working because of COVID-19	9	7.4%
Hasn't worked since before COVID-19	47	39.3%
Father's employment situation during the critical period of the COVID-19 pandemic		
Commuting regularly to work	56	46.7%
Working from home	35	28.7%
Not working because of COVID-19	14	11.5%
Hasn't worked since before COVID-19	16	13.1%
Being an only child		
Yes	54	41.26%
No	68	55.74%
Verbal language level of the child/adolescents		
Fala fluentemente	48	39.3%
Speaks few words or not	53	43.4%
Do not speak	21	17.2%
Presence of comorbidities		
Yes	29	18.85%
No	93	81.15%
Pharmacological treatment for behavioral/sleep problems		
Yes	60	49.18%
No	62	50.82%
Type of school participants attend		
Private	80	65.57%
Public	30	24.59%
Does not attend	12	9.84%
Child/adolescents receives therapy*		
Private		51
Health insurance		70
Unified Health System (SUS Brazil)		28
Doesn't receive		9

*More than one option was possible.

Table 2 provides an overview of the participants regarding the psychological and behavioral impact of children and adolescents with autism spectrum disorder (ASD). In relation to COVID-19 infection and death, 28.7% of families had a member who tested positive during the study period and 20.5% lost someone for the disease.

According to caregivers, 47.54 per cent of young people with ASD had behavioral problems before the pandemic. The interruption of multi-professional intervention services occurred in 87.70% of cases, and may have had a significant impact on the management of ASD during the pandemic, considering that 44.26% of families sought specialized support from neurologists or psychiatrists due to behavioral issues during the survey period. In this sense, 87.70% of participants, according to the view of caregivers, showed regression of development and worsening of the symptoms associated with ASD.

Meal management presented an almost equal division between those who faced difficulties and those who did not. More than half of the participants (54.9%) problems in the management of autonomy, indicating that the pandemic may have had a negative impact on the independence of children and adolescents with ASD. Time management was the most affected area, with most reporting difficulties (80.6%), which may be related to changes in daily routines and the need to adapt to new formats of teaching and therapy.

School support varied significantly, with a considerable number of students receiving daily contact (34.70%), but many also without frequent contact. While therapeutic support was generally inadequate, with most families reporting lack of frequent contact (45,08%). The majority of families an increase in the intensity (61,5%) and frequency (59.8%) of behavioral problems of children with ASD during the pandemic.

Table 2. Psychological and behavioral impact of children and adolescents with ASD and their families during the COVID-19 pandemic, Ceará, 2020/2021.

Positivity for COVID-19 in a family member		
Yes	36	29.51%
No	86	70.49%
Death in the family due to COVID-19		
Yes	25	20.49%
No	97	79.51%
Had behavioral problems before the COVID-19 pandemic (disruptive behaviors)		
Sim	58	47.54%
No	64	52.46%
Multiprofessional intervention services were interrupted		
Yes	107	87.70%
No	15	12.30%
Contacted the child's neuro/psychiatrist due to behavioral issues		
Yes	54	44.26%
No	68	55.74%
Showed regression of development compared to before the COVID-19 pandemic		
Yes	107	87.70%
No	15	12.30%
Greater difficulty managing meals than before the COVID-19 pandemic		
Yes	57	46.72%
No	65	53.28%
Problems in managing autonomy compared to before the COVID-19 pandemic		
Yes	69	56.56%
Não	53	43.44%
Difficulty managing time compared to before the COVID-19 pandemic		
Yes	106	86.89%
No	16	13.11
Receiving school support		
Daily contact	46	37.70%
No frequent contact	37	30.33%
Weekly contact	31	25.41%
Contact twice a week	8	6.56%

A multiple logistical regression tested for the effects of the variables: (I) pre-emergency behavioral problems (yes/no), (II) age, (III) language (fluent/not fluent), (IV) being a single child (yes / no) as a proxy for greater social isolation in quarantine, (V) medical comorbidity (yes or no), (VI) parental status (married or cohabiting/separated or single parent), (VII) support of multi-professional therapeutic services during the COVID-19 pandemic (yes and no), and (VIII) direct school support (yes & no), on the intensity of behavior problems after the outbreak of Covid-19 (more intense or less intense).

The logistic regression model was statistically significant, $\chi2(10, N = 122) = 23,96, p < 0,005$. Individuals with ASD and who had pre-existing behavioral problems were 3.86 times more likely to exhibit more intense behavioral problems than those without pre-existent behavior problems. Being a single child has been associated with a reduced chance of presenting more intense behavioral problems in relation to someone who has one or more siblings (Table 3).

Table 3. Predictors of the negative impact of social isolation due to COVID-19 on the *intensity of behavior* problems.

	OR	p-value	95% CI
Age	1.00	0.98	0.85 – 1.17
Couple's situation	0.48	0.31	0.12 – 1.98
Behavioral problems before the pandemic	3.42	0.05	1.02 – 11.52
Only child	0.08	0.00	0.02 – 0.33
Language	0.72	0.62	0.20 – 2.63
Medication use	1.35	0.62	0.41 – 4.43
Multiprofessional therapeutic support	1.72	0.40	0.49 – 6.00
Direct school support	0.53	0.32	0.15 – 1.85

Note: OR, Odds Ratio; CI, Confidence Interval.

Another multiple logistic regression was tested with the same previous predictive variables on the frequency of behavioral problems after the outbreak of COVID-19 (more intense or less/equally intense). The logistic regression model was statistically significant, $\chi2(10, N = 122) = 24.55$, $p < 0.005$. Individuals with ASD and who had pre-existing behavioral problems were 3.42 times more likely to exhibit more frequent behavior problems than those without pre-existent behavioral problems, while being a single child was also significantly associated with a reduced chance of having more common behavior problems compared to non-single children (Table 4).

Table 4. Predictors of the negative impact of social isolation due to COVID-19 on the *frequency of* behavior problems.

	OR	p-value	95% CI
Age	1.01	0.90	0.85 – 1.21
Couple's situation	0.65	0.59	0.13 – 3.14
Behavioral problems before the pandemic	3.87	0.05	1.01 – 14.83
Only child	0.16	0.02	0.04 – 0.70
Language	0.95	0.94	0.22 – 4.07
Medication use	1.54	0.53	0.40 – 5.92
Multiprofessional therapeutic support	3.68	0.10	0.80 – 16.92
Direct school support	0.35	0.13	0.09 – 1.37

Note: OR, Odds Ratio; CI, Confidence Interval.

DISCUSSION

The mean age of children in the present study is within the age group known as preschool. Children of this age worsened behavior problems and increased repetitive interests and/or activities the most during the pandemic, according to a survey with family members.[7] The participating families mostly lived in urban areas, which can be justified by several reasons, including: the need to facilitate frequent travel between home/care institutions and the therapy services that children with ASD need, especially for those with low financial income; due to the fact that specialized physicians mostly work in cities and therefore the volume of individuals diagnosed with ASD is greater, or simply because of the study's methodological problem, that is, not many respondents in the rural area.

The distribution of family income shows that a considerable proportion of families live on modest income. Although the specific effects of the pandemic on parents' incomes have not been directly investigated, it is known that families of children with ASD face a 21% reduction in income compared to families of kids with other health constraints and 28% compared with families with children with no health restrictions.[7,8] This financial disparity may result in additional challenges, in prioritizing critical areas such as health and education. Paradoxically, most children in our sample attend private schools and have private health plans.

Considering the low monthly income of almost half of the families, it is possible that they face difficulties to find a financial balance and, even so, direct their resources to areas considered priority, such as health care and the education of the child with ASD.

This study identified that female caregivers, in general, mothers, stayed at home longer due to the pandemic, either because they work from home or because they do not have a formal job. According to Cidav, Marcus, Mandell, (2012),[8] on average, mothers of children with ASD earn 35% less than mothers of children with other health limitations and 56% less than mothers of children without health limitations, due to working fewer hours per month or not having a formal job. We also found more unemployed mothers than fathers. In fact, mothers, as primary caregivers of children with ASD, are more likely to give up a professional career to care for their children, even if they have a higher level of education than fathers.[9] Unemployment is one of the factors that contributed to increased risk of symptoms of anxiety and depression in mothers of children with ASD during the first wave of COVID-19 in 2020 in Italy.[7]

Despite the increased risk of divorce between parents of children with disabilities compared to parents of non-disabled children,[10] in our sample most children with ASD (73.8%) lived with married or cohabiting parents. Family support, especially in households where parents are together, can positively influence the management of ASD. However, another research has identified that living with one parent, whether separated or single, has been associated with better well-being in during the period of social isolation,[6] and this may be due to a more simplified interaction between parents and children.

The present study revealed that being a single child can be a protection against the worsening in the intensity and frequency of behavioral problems in young people with ASD, this data was statistically significant. Strengthening this finding, a study similar to ours found that being a single child was not associated with an increase in the severity or frequency of behavioral problems in children with ASD during the first wave of COVID-19.[6] Which can be attributed to the fact that these individuals already usually face greater social isolation, or because they receive exclusive care from caregivers.

The transition to online education has represented a significant challenge for both parents and people with ASD, further reducing social interaction and potentially contributing to feelings of loneliness.[6] In line with these findings, the present study indicated that 31.1% of children with ASD had no contact with school during the pandemic.

In the study by Colizzi *et al*. (2020),[6] individuals with ASD who received school support during the COVID-19 outbreak, for example, through phone calls, video calls, text messages and homework, tended to express less intense behavior problems, suggesting the importance of remaining in contact with the school during the emergency.

The closure of schools and lack of access to therapies can lead to a significant increase in the difficulty of managing the leisure time of children with ASD, with consequences such as increased screen use and reduced physical activity.[11]

During the pandemic, 86.9% of parents and caregivers encountered difficulties in managing their children's leisure time, with 80.6% reporting an increase in these problems due to COVID-19. In addition, 86.1% highlighted greater challenges in managing structured activities compared to the pre-pandemic period. This situation also has repercussions on the increase in the emotional burden and stress of parents, which are already high for parents of children with ASD and the pandemic has made the situation more complex. The study by Sartor *et al*, 2023[12] shows that the worsening of ASD symptoms in children seems to be a central factor for the increase in parental stress in this period.

The interruption of therapeutic interventions during social distancing reached more than 87% of our sample. This interruption has a negative impact on the quality of life of children with ASD and their parents or caregivers, especially of those with greater severity of ASD symptoms, as it is associated with worsening symptoms related to repetitive behaviors, interests or activities.[7]

Corroborating the above, this study shows that more than 80% of parents stated that their children had regression in some aspect of development. The abrupt interruption of routines, social activities and therapies, together with the reduction in social interaction, can cause confusion and emotional disorganization in many individuals with ASD, resulting in regression in social and emotional behaviour.[13]

It is known that children with ASD have characteristics according to the degree and also according to exposure to treatment.

In view of this, one of the most common clinical manifestations in individuals with ASD is related to nutrition. Parents and caregivers usually report difficulty in managing meals due to food selection and refusal.[14] In view of this, 45.9% of parents and caregivers stated that they already had difficulties in managing meals. However, these aspects worsened with the pandemic, with greater impact on families with lower income, due to facing, in addition to other difficulties related to the financial aspect, food insecurity.[15] This was pointed out by 39.3% of participants, who reported greater difficulties in managing their child's meals compared to before COVID-19. It is important to note that parental distress can affect the emotional and adaptive behavior of both neurotypical and autistic children, and the consequence can be a vicious cycle of distress and stress between parents and children.[16]

This study reinforces the notion that the pandemic has brought challenges to the whole family, and that parental suffering can, in turn, impact their children's well-being.

It has been shown that children with ASD during the pandemic had a significant increase in challenging behavior during the pandemic. These behavioral changes included generalized anxiety, irritability, and opposition behavior.[17] Individuals who had disruptive behavior prior to the pandemic were more likely to experience an increase in the intensity and frequency of these problems.[6] In accordance with these findings, the most significant results of the present study are that individuals with ASD with behavioral problems prior to the outbreak of COVID-19 are three times more likely to have more intense and frequent behavior problems (disruptive behaviors) compared to the period before the COVID-19 pandemic.

In this study, 54.9% of participants reported that there were greater difficulties in managing the child's autonomy compared to periods prior to the COVID-19 pandemic. The problematic management of children's autonomy seems to be related to the breaking of routines and the difficulty in accessing therapies and health treatments faced in the period. A progressive adaptation to the new reality can be carried out in a structured way at school, with caregivers and with therapeutic services for the return to a new routine and access to therapeutic services.[18]

The analysis of logistical regression data seeks to identify predictors of the negative impact of social isolation due to COVID-19 on the intensity of behavioral problems in children and adolescents with ASD. In this sense, the main result of this study is that individuals with ASD who presented behavioral problems before the outbreak of COVID-19 are almost four times more likely to experience an intensification in the frequency of these problems ($OR = 3,87$, $p = 0,05$) and almost three and a half more chances increase in the frequency ($OR = 3,42$, $p = 0.05$) of behavior problems. This finding is consistent with existing literature, which indicates that additional stress caused by traumatic or disruptive events, such as a pandemic, may exacerbate pre-existing behavioral problems in children with ASD.[6]

On the other hand, the study identified that being a single child can act as a protective factor against the negative impact of social isolation, with a significant reduction in the chance of intensification ($OR = 0,16$, $p < 0,05$) and frequency ($OR = 0,08$, $p < 0,01$) of these problems. This finding is supported by studies that indicate that the absence of siblings can reduce the level of conflict and stress in the domestic environment, providing a more stable and less conflicting experience during periods of isolation.[19]

Although the pandemic has presented significant challenges, there have also been reports of positive impacts in aspects such as communication and socialization, attributed to an increase in family cohabitation time and the search for creative alternatives to maintain connection with other people.[13] Health professionals and educators are essential to providing continuous support and tailored strategies to assist children with ASD during challenging periods such as the COVID-19 pandemic.

The limitations of this study include those typical of descriptive studies that predominantly describe phenomena without establishing causal relationships between variables. Sampling for convenience may limit the generalization of the results, especially considering that the questionnaire has not been translated or validated, and has been applied predominantly in urban areas, not necessarily representing the reality of rural areas.

The findings cannot be extrapolated to the Brazilian reality and further studies are needed to establish inclusive and multidisciplinary public policies for patients with ASD during pandemic periods or health crises. Although accessible at a distance, they will potentially reach those who do not live in large centers and are more subject to the inequities and disparities generated by Brazil's continental dimensions.

CONCLUSION

Our findings showed a large proportion of caregivers reporting difficulties related to access to therapies and school resources. In addition, major changes in the behavior, eating and self-care patterns of children and adolescents with ASD often occurred during the period of social distancing, however, we emphasize that the most significant finding of this study is that individuals with ASD who had behavior problems before the COVID-19 outbreak are more likely to experience an intensification in the frequency and severity of these problems, while being an only child may act as a protective factor against the negative impact of social isolation on behavior problems.

As the future need for new periods of social distancing is still unknown, the search for the development of effective strategies to mitigate the negative impact of a new pandemic must be one of the priorities for public policy makers, schools, and health plans.

The authors would like to emphasize that not all families will need additional support during the social distancing period, but identifying vulnerable families with this need should represent a priority for reducing the social, psychological, and neurodevelopmental suffering of people on the autism spectrum and their families.

Conflicts of Interest

The authors report no conflicts of interest.

REFERENCES

1. Smile SC. Supporting children with autism spectrum disorder in the face of the COVID-19 pandemic. CMAJ. 2020;192(21):E587. doi: 10.1503/cmaj.75399.
2. American Psychiatric Association. Neurodevelopmental disorders. In: American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. revision of the text). 2020. doi: https://doi.org/10.1176/appi.books.9780890425787.x01_Neurodevelopmental_Disorders.
3. Lima DLF, Dias AA, Rabelo RS, Cruz ID, Costa SC, Noronha FM, et al. COVID-19 no estado do Ceará, Brasil: comportamentos e implicações na chegada da pandemia. Ciênc Saúde Colet. 2020;25:1575-86. doi: 10.1590/1413-81232020255.07192020.
4. Ribeiro EG, Souza EL, Nogueira JO, Eler R, Moura FRM. Saúde mental na perspectiva do enfrentamento à COVID-19: manejo das consequências relacionadas ao isolamento social. Rev Enferm Saúde Colet [Internet]. 2020 [acesso em 20 ago. 2023];5:47-57. Disponível em: http://revesc.esy.es/index.php/revesc/article/view/59/68
5. Ferreira NSP. Qualidade de vida dos familiares de pessoas com transtorno do espectro autista [dissertação]. Macapá: Universidade Federal do Amapá; 2018.
6. Colizzi M, Sironi E, Antonini F, Ciceri ML, Bovo C, Zoccante L. Psychosocial and behavioral impact of COVID-19 in autism spectrum disorder: an online parent survey. Brain Sci. 2020;10(6):341. doi: 10.3390/brainsci10060341.
7. Logrieco MG, Casula L, Ciuffreda GN, Novello RL, Spinelli M, Lionetti F, et al. Risk and protective factors of quality of life for children with autism spectrum disorder and their families during the COVID-19 lockdown. An Italian study. Res Dev Disabil. 2022 Jan;120:104130. doi: 10.1016/j.ridd.2021.104130.
8. Cidav Z, Marcus SC, Mandell DS. Implications of childhood autism for parental employment and earnings. Pediatrics. 2012;129(4):617-23. doi: 10.1542/peds.2011-2700.
9. Zhou W, Liu D, Xiong X, Xu H. Emotional problems in mothers of autistic children and their correlation with socioeconomic status and the children's core symptoms. Medicine (Baltimore). 2019;98(32):e16794. doi: 10.1097/MD.0000000000016794.
10. Hartley SL, Barker ET, Seltzer MM, Floyd FJ, Greenberg JS, Orsmond GI. The relative risk and timing of divorce in families of children with an autism spectrum disorder. *J Family Psychol*. 2010;24(4), 449-57. doi: 10.1037/a0019847.
11. Garcia JM, Lawrence S, Brazendale K, Leahy N, Fukuda D. Brief report: The impact of the COVID-19 pandemic on health behaviors in adolescents with Autism Spectrum Disorder. Disabil Health J. 2021;14(2):101021. doi: 10.1016/j.dhjo.2020.101021.
12. Sartor T, Sons S, Kunina-Habenicht O, Tröster H, Kuhn JT. Demands and stress before and during the COVID-19 pandemic of parents to children with autism spectrum disorder. Front Psychol. 2023;14:1212556. doi: 10.3389/fpsyg. 2023.1212556.
13. Friesen KA, Weiss JA, Howe SJ, Kerns CM, McMorris CA. Mental health and resilient coping in caregivers of autistic individuals during the COVID-19 pandemic: findings from the families facing COVID study. J Autism Dev Disord. 2022;52(7):3027-37. doi: 10.1007/s10803-021-05177-4.
14. Carvalho JA, Santos CSS, Carvalho MP, Souza LSA. Nutrição e autismo: considerações sobre a alimentação do autista. Rev Cient ITPAC. 2012;5(1):Pub1.
15. Panjwani AA, Bailey RL, Kelleher BL. COVID-19 and behaviors in children with autism spectrum disorder: Disparities by income and food security status. Res Dev Disabil. 2021 Aug;115:104002. doi: 10.1016/j.ridd.2021.104002.
16. Levante A, Petrocchi S, Bianco F, Castelli I, Colombi C, Keller R, et al. Psychological impact of COVID-19 outbreak on families of children with autism spectrum disorder and typically developing peers: an online survey. Brain Sci. 2021;11(6):808. doi: 10.3390/ brainsci11060808.
17. Bozkus-Genc G, Sani-Bozkurt S. How parents of children with autism spectrum disorder experience the COVID-19 pandemic: perspectives and insights on the new normal. Res Dev Disabil. 2022;124:104200. doi: 10.1016/j.ridd.2022.104200.
18. Jacques C, Saulnier G, Éthier A, Soulières I. Experience of autistic children and their families during the pandemic: from distress to coping strategies. J Autism Dev Disord. 2022;52(8):3626-38. doi: 10.1007/s10803-021-05233-z.
19. Wang G, Zhang Y, Zhao J, Zhang J, Jiang F. Mitigate the effects of home confinement on children during the COVID-19 outbreak. Lancet. 2020;395(10228):945-7. doi: 10.1016/S0140-6736(20)30547-X.

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