

IMPACTS OF THE COVID-19 PANDEMIC ON CHILDREN AND ADOLESCENTS WITH AUTISM SPECTRUM DISORDER AND THEIR CARING PARENTS

Gabriela Oliveira dos Santos

Universidade Estadual do Sudoeste da Bahia-
UESB

Jequié - BA

<http://lattes.cnpq.br/5921976428664102>

Laiane Santos de Jesus

Universidade Estadual do Sudoeste da Bahia-
UESB

Jequié - BA

<http://lattes.cnpq.br/3722232943175965>

Victória Bomfim Santos

Universidade Estadual do Sudoeste da Bahia-
UESB

Jequié - BA

<http://lattes.cnpq.br/0798766392605114>

Natália Ribeiro de Moraes Souza

Universidade Estadual do Sudoeste da Bahia-
UESB

Jequié - BA

<http://lattes.cnpq.br/4994864784396876>

Camila Rego Amorim

Universidade Estadual do Sudoeste da Bahia-
UESB

Jequié - BA

<http://lattes.cnpq.br/7615435486675940>

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Sumaya Medeiros Botelho

Universidade Estadual do Sudoeste da Bahia-UESB

Jequié - BA

<http://lattes.cnpq.br/2807049197454578>

Nayara Alves de Sousa

Universidade Estadual do Sudoeste da Bahia-UESB

Jequié - BA

<http://lattes.cnpq.br/0962407121731621>

Lorena Couto Lobo

Universidade Estadual do Sudoeste da Bahia-UESB

Jequié - BA

<https://lattes.cnpq.br/3231083390167590>

Isnara Teixeira de Britto

Universidade Estadual do Sudoeste da Bahia-UESB

Jequié - BA

<http://lattes.cnpq.br/8086473082473509>

Abstract: Introduction: The COVID-19 pandemic has generated abrupt changes in the lives of children/adolescents with ASD, impacting the entire family environment, with consequences that can be quite negative. The aim of this study was to analyze the consequences of the COVID-19 pandemic period in the lives of children/adolescents with ASD and their caregivers. **Methods:** This is a descriptive study with a qualitative approach. Parents of children/adolescents with ASD who were being treated at the location were eligible for the sample. Children and/or adolescents with ASD who reside in institutions or who did not regularly attend the institution before the pandemic were included in this research. The interviews were analyzed using Bardin's content method, with the following categories emerging: impacts of the pandemic period on children/adolescents with ASD (1), with three subcategories, namely: impacts on family routine, behavioral impacts and physical impacts; Remote teaching and children/adolescents with ASD (2); Repercussions of the pandemic period on the caregiver(3). **Results:** All interviewees were mothers of children/adolescents with ASD. Some interviewees mentioned that their family routine was directly impacted by the pandemic. 90% reported that their children showed behavioral worsening during the pandemic, while 40% reported that their children were also physically impacted by the period, mainly due to weight gain. In face of remote teaching, 60% of the interviewees reported the difficulty faced in carrying out the proposed activities. All mothers reinforced that they felt changes in their personal routine, in addition to the fear of not being offering the proper treatment to their children. **Final considerations:** The study identified that the pandemic had several impacts on the lives of children

and adolescents with ASD and on those responsible for them. With the return of activities and institutions, it is expected that it will be investigated how these impacts may have influenced the return to routine of these families.

Keywords: Caregivers; Covid-19; Country; Pandemic; Autism Spectrum Disorder

INTRODUCTION

In March 2020, the World Health Organization (WHO) established COVID-19 as a global pandemic. As a result, negative repercussions were triggered in the lives of people around the world, including gaps involving mental health¹. The psychological suffering promoted by the pandemic period can have even more significant repercussions on people with pre-existing mental disorders, including Autistic Spectrum Disorder (ASD)².

ASD can be characterized as a neurodevelopmental disorder with deficits in communication and social integration, with specific and repetitive patterns of behavior. In addition, one of the main characteristics is the preservation of a detailed and punctual routine³.

The prevalence of ASD is 1 in 44 in children up to eight years old⁴, being 4x more prevalent among male children⁵ and that most have associated intellectual disability and other psychiatric conditions, including anxiety disorders, ADHD and depressive disorder⁶. In view of this, this population has a greater tendency to develop, during the pandemic, impacts on health by breaking the routine and support of care in schools, clinics and other institutions, interrupted as a way to contain the spread of the disease.⁷

At the beginning of the pandemic, studies and scientific research turned to discovering the ways of preventing, contagion and other factors of COVID-19. As research progressed, several impacts of this period on the general

population were observed, including those involving mental health and physical well-being.²

Staying at home, not attending school or relying on the support of professionals, promotes stressful situations for people with disabilities and their families. With interrupted routines and the absence of support networks, caregivers were asked to carry out work without sufficient theoretical and practical training, impacting the entire family environment, with consequences that could be quite negative.⁸

To date, the topic addressed in studies, for the most part, only involves how children and adolescents with ASD were impacted by the pandemic, with questionnaires aimed at this group, relativizing the negative repercussions of the pandemic period on their caregiver parents. In fact, the focus of the research was on these children and adolescents, however, the impacts and repercussions on the entire family environment were also considered, especially on the lives of caregivers. From this perspective, the present study aimed to analyze the consequences of the COVID-19 pandemic period in the lives of children/adolescents with ASD and their caregivers.

METHODS

This is a descriptive study with a qualitative approach. The research was carried out at the Associação de Pais Amigos Excepcionais (APAE) located in the municipality of Jequié, Bahia. The population consisted of 10 parents who care for children and/or adolescents diagnosed with ASD, aged between 02 and 18 years old, attended at APAE, which took place from June to July 2022.

Parents of children and/or adolescents with ASD who were being treated at APAE were eligible for the sample. Children and/or adolescents with ASD who reside in institutions or who did not regularly attend

the institution before the pandemic were included in this research.

Participants were informed about the objectives, justification, risks and benefits of the study so that, if they agreed, they could sign the Free and Informed Consent Form (TCLE), with the guarantee of secrecy of the information provided.

After signing, the sociodemographic questionnaire was applied, followed by a semi-structured interview, developed by the research authors, with questions about the child's routine and family dynamics before and during the pandemic period; as well as a free space at the end of the interview for the participant, if he deemed it necessary, to talk about some information he considered important and which he was not asked directly.

The interviews were recorded by cell phone so that no information was lost, stored in a safe place, with no access to people who were not directly involved in the research and, later, heard and transcribed in full for analysis. At all times, we sought to fully preserve the anonymity of the participants, so the evocations of the participants were given through the letter P, followed by numbers from 1 to 10.

The interviews were analyzed according to Bardin's content analysis method. According to Bardin, content analysis is a set of communication analysis techniques and its application covers the following domains:

1) The nature of the linguistic support codes (written and oral), iconic (signs, graphics, images, photographs, films, etc.) and other semiotic codes (everything that is not linguistic and can be a carrier of communication).⁹

Then, the floating reading of the interviews was carried out, where contact with the material to be analyzed was established, letting oneself be invaded by impressions and guidelines. In the material exploration stage, more in-depth readings were carried out, with everything that was significant and having the same thematic content being marked.

In the phase of treatment, inference and interpretation of results, the recording units were cut at the semantic level and, later, grouped, thus emerging three categories, as described below: (1) impacts of the pandemic period on children/adolescents with ASD, with three subcategories, namely: impacts on family routine, behavioral impacts and physical impacts; (2) Remote teaching and children/adolescents with ASD; (3) Repercussions of the pandemic period on the caregiver.

The study was approved by the Research Ethics Committee of the State University of Bahia – CEP/UESB, under opinion number 5,422,252, following the ethical precepts of CONEP Resolution Number 466/2012 regarding research involving human beings.

RESULTS AND DISCUSSION

Sex	Age	Family composition	Scholarity	Family income
Feminine 100% (n=10)	Between 34 and 42 years old, with a predominance of the age group between 39 and 42 years old.	3 people: 50% (n= 5) 4 people: 20% (n=2) 5 people: 20% (n=2) 2 people: 10% (n=1)	Complete higher education: 20% (n=2) Complete high school: 50% (n=5) E.F. Incomplete: 10% (n=1) Unable to inform: 10% (n=1)	1 minimum wage: 80% (n= 8) >2 minimum wages: 10% (n=1) <1/2 minimum wage: 10% (n=1)

Table 1: sociodemographic description of the sample.

Source: Research data.

Among the main findings of the table described above is the fact that 100% of the interviewees were mothers. In general, the birth of a child with a disability has repercussions in different family areas, due to changes, doubts, among other feelings.

When confirming a child with a disability, care is even greater, considering a turning point in the parents' lives. Most of the time, the mother is the main caregiver from the birth of that child until aging. One of the reasons for this is that, culturally, the paternal role and influence are not so valued and, many times, the mother herself is judged to be the main responsible for having generated this child. This way, the overload in these mothers' lives tends to be more evident, since more intense changes occur in all aspects of caring for the child, from professional and personal aspects¹⁰.

In addition, it is possible to note that 90% of the participants reported that the family income is equal to/less than the minimum wage and that these findings may have directly influenced the changes related to the pandemic period. In the study by Stadheim et al, most parents interviewed who described that their children were doing well during the pandemic also reported an above-average family income. This possibility of working at home is more common in families with higher purchasing power, but even so, it was not possible to determine, in fact, the influence of family income in the pandemic perspective, considering that the majority of this sample is from Caucasian families with medium and high incomes.

IMPACTS OF THE PANDEMIC PERIOD ON CHILDREN/ADOLESCENTS WITH ASD:

Impacts on family routine

In the face of the pandemic, schools, associations, clinics, social living

environments were abruptly closed, without prior notice, so the routine of these families had to undergo adaptations in educational activities, treatment and leisure activities. In the evocations of the caregiver parents, it is possible to observe how these changes were perceived, when they emphasized that their children missed these moments and the contact with other environments and people and that, many times, they did not understand the reason for the change, failing to attend and have access to spaces that were part of their daily routine.

“It broke our whole routine, everything got messy. And for them, who need this routine to be followed, it was quite messy, and we are still fixing it [...] It was a very big impact, it was that sudden change, without prior notice (E2).”

“People go out a lot. Every weekend we go out. He loved going out, so for him it changed everything. He was very sorry, when I wore clothes he wanted to leave right away (E3).”

In the study by Meral B. F., parents of children with ASD reported that isolation and little or no interaction between peers significantly impacted their children during the pandemic. The children wanted to go out, however, during the curfew, access to public places became limited and, for many moments, prohibited¹¹.

The routine of the general population during this period was changed, but in the routine of children/adolescents with ASD, the restriction may have been even greater, as the spaces they most frequented in the pre-pandemic period, which were part of their treatments and contributed to their socialization and evolution were closed and public spaces for interaction such as squares and parks were also prohibited from circulating, leaving them restricted to family life.

It is known that the child/adolescent with ASD needs daily these moments of coexistence with other children of the same age group, frequenting environments with rules and routines that allow sensory, motor and cognitive stimulation as part of their routine.

Behavioral impacts

Changes in routine caused by the pandemic can often represent a significant challenge for people with ASD and, consequently, these families may be more likely to develop anxiety and other mental disorders.³ Discontinuing services and therapies without prior notice, in addition to other factors, may result in aggravation of autism symptoms, as well as a decrease in mental well-being.²

In fact, the atypical period of the pandemic brought about behavioral changes in most of these children and adolescents. When analyzing the speeches, only 1 respondent (10%) reported that her child had developed a behavioral improvement, while 9 (90%) noted that the main perceived changes were increased anxiety, stress and agitation. In this regard, it was possible to highlight:

“During the pandemic, to tell you the truth, he was more stressed in the case, because he wasn't going to places, you know? He was trapped. And not today, he goes out, he goes to day care, he comes here. He was more nervous, agitated indoors, because he really doesn't like to be stuck indoors. He wants to go out, he wants to go to other places (E5).”

Similar results were evidenced in a study by Bozkus-Genc, G. et al, identifying that among the negative aspects related to the atypical moment promoted by the pandemic are the behavioral ones. Parents reported during the interviews that their children became more solitary and less communicative, with fear, increased stress and self-injurious behavior being the most noticeable changes.¹²

The decrease in social contacts, interruption of therapies, fears of contamination and closure of schools and institutions, directly impacted these children's routine, radically changing it in most families. Faced with the need for children and adolescents with ASD to have established routines that, in most cases, need to be followed punctually, this sudden change may have triggered stressors that stimulated behavioral change in these individuals.

Physical impacts

In the face of the pandemic, physiotherapeutic calls were also interrupted. As a result, sensory behaviors that, until then, had been controlled, began to be observed, as was clear in the speech of a mother who reported fear of walking on tiptoe that her daughter was no longer performing before the moment of interruption of activities physiotherapeutic.

“[...] Physical therapy, one of them didn't do that much, but then the pandemic came, it intensified her problem a lot, now she's doing this treatment more intensely, to try to come back, because she lost a lot. Before the pandemic she was able to step normally, after the pandemic she is now walking completely on her toes. She actually regressed (E2) ”.

Motor difficulties, including fine and gross motor skills, represent an important factor in many cases of ASD. However, it is recognized that, until the present moment, there are several limitations to analyze such factors, including the fact that, traditionally, ASD is not characterized as a physical disease, configuring it only as the product of other dysfunctions, mainly behavioral and neuropsychiatric. For this, it is highlighted that the best way is to raise awareness, especially, of health professionals about the theme¹³.

In some families, physical activities are no longer considered part of the routine or remain limited by the moment they are experiencing. The sedentary lifestyle, added to other factors, such as, for example, the increase in screen time, which was evidenced in part of the statements, led some children and adolescents to develop weight gain. 30% of mothers reported that their children started to eat more, a factor that may be linked to the increased level of stress and anxiety that the period of social isolation provided in the lives of these children and adolescents.

“[...] he gained weight, he was very skinny. Because in the pandemic he didn't do activities, so he stayed indoors more, he wouldn't even go to the corner of my house street, not even with someone, I called him to ride a bike, I said there was no one on the street and he still I wouldn't. (E6)

For the general population, overweight and obesity are public health problems. Many chronic diseases in adulthood can be directly associated with pediatric obesity, such as the cardiovascular disease and diabetes. Particularly children and adolescents with ASD and ADHD may be even more prone to the risk of obesity and overweight, presenting a higher risk compared to the general population.¹⁴

In the present study, only 40% of the interviewees noticed physical changes in their children's lives in the face of the pandemic, which may be a justification for the lack of studies that show these impacts, which, many times, may have been similar results in other studies and, therefore, were disregarded because they were not factors perceived in most of the interviews carried out.

Remote teaching and children/adolescents with ASD

When asked about remote teaching during the pandemic, mothers said that all schools, including private (30%) and municipal (70%), adopted the online methodology. When analyzing the speeches, it is possible to notice the difficulty found by most mothers (60%), mainly in relation to the adaptation process and the concentration of these children and adolescents during activities:

“He couldn't adapt. He couldn't attend classes, he kept saying that he was tired, that he couldn't [...] He was late in this period. Before, he was already writing in cursive, but after the pandemic he went back to writing in block letters (E9).”

Individuals with ASD may have greater difficulty staying in front of a computer screen or concentrating when performing proposed activities. The lack of physical contact with teachers and colleagues, as well as the mothers' difficulty in carrying out activities were also highlighted in the evocations of these interviewees.

“The remote he learned nothing. I couldn't keep up. I did, but it didn't come out the same thing that was in the video as the girls did [...] what his caregiver told me, I didn't know, I didn't have that understanding to do with him. I did, but I didn't do the same thing (E4).”

Different from the findings in the present study, a survey carried out by Amirova, A. et al, identified that all parents unanimously were against online learning, in addition to showing that parents were forced to deal with the various responsibilities imposed without having adequate training, generating an increase in stressors during the pandemic period¹⁵.

One of the possibilities for the result of the present study to have been different from the one described above is that mothers who did not find difficulties in relation to remote

teaching (40%) sought strategies so that their children could concentrate, taking advantage of the moment to encourage their children, which includes the possibility to continue teaching even if remotely, in addition to maintaining virtual contact with colleagues, facilitating the socialization of these children and adolescents, as is clear in the following speech:

“The activities he was able to do. He only developed because I didn’t give up on him, I didn’t wait to come back to encourage him, which I thought would help him, I encouraged him. So if he likes math, then I would do everything for that (E6).”

Similar to this, Stadheim, J. et al conducted a survey of parents of children and adolescents aged 3 to 18 years, highlighting the transition from face-to-face learning to remote learning. For some, this transition provided a protection factor, promoting fundamental resources to adapt to the changes imposed by the period¹⁶.

Repercussions of the pandemic period on the caregiver

Most parents had to deal, without adequate assistance, with several emotional and functional aspects, in addition to behavioral problems. Parenting skills can be affected by changes in children’s behavior, such as increased disobedience or changes in mood. Parents are faced with an increased burden, which can trigger mental and physical problems¹⁷.

With the pandemic, the changes in every routine, added to the absence of support institutions, accumulation of demands and the physical and emotional overload that the period itself imposed on society in general, made these caregivers feel even more impacted. When questioned about how they, as mothers and caregivers of children and adolescents with disabilities, find themselves

emotionally, the most present answers were those of fear, insecurity and incapacity.

“Emotionally speaking, I felt like my hands were tied, not knowing what to do, we try to do what we can, but at some point we feel guilty for not being able to do more. I did what was possible and what they let me do (E2).”

“There are people in the pandemic who didn’t go through this and went into depression. I asked God not to fall, not to be too sad, because I am his strength (E6).”

In some speeches, it was possible to highlight the feeling of guilt for not knowing how to offer the necessary services for the development of these children and adolescents, added to the fear of being infected and infecting their children. All interviewees reported that, since before the pandemic, their children had been carrying out pedagogical and psychological activities, among others, being well monitored and guided.

With activities interrupted due to the pandemic, these caregivers were faced with a new challenge: adapting to the new reality. With the absence of direct contact with these professionals, some mothers brought up the various barriers that arose during this period, mainly regarding the lack of practical handling or the fear of doing it inappropriately, as they needed to perform new tasks and functions that they would never imagine performing, as it is punctuated in the speech of this mother:

“I did a lot of things, I was always evaluating, the whole time [...] I had to be a little bit of everything. I was a teacher, I was a physiotherapist, a psychologist (E3).”

Regarding the changes triggered by the pandemic moment and whether there were changes in their routines, including physical and behavioral impacts, all mothers reported that yes, and in one of these statements it was possible to highlight:

“I gained a lot of weight [...] I was very stuck. I was very scared because I had my children and my parents, who are hypertensive, so I had to be cleaning all the time, avoiding people coming home, so it ends up being very stressful. I also went to the cardiologist, I needed to take medicine, he said he would give me some medicine to calm me down (E7).”

Similar results were found in the study by Fridell, A. et al, which identified several parents with greater stress due to increased pedagogical responsibilities, especially in the face of remote teaching. Another stressor was due to the parents' difficulty in properly carrying out the proposed activities and in dealing with the new routines imposed on their children during the pandemic, adapting to changes in routines that, until then, were regular, identifying that some children develop adverse responses, with many parents reporting that, when compared to face-to-face modalities, learning and/or intervention carried out online were ineffective or less ineffective¹⁸.

FINAL CONSIDERATIONS

The study identified that the pandemic had several impacts on the lives of children and adolescents with ASD and on their caregivers. Among the main impacts, the behaviors and difficulties faced in the process of adapting these individuals to remote teaching stand out, as well as the impact of changing the family routine. It is important to emphasize that the mothers of these children and adolescents had several limitations, especially due to the increase in demand and the lack of support from trained professionals, reporting the fear of not offering adequate treatment to their children.

Because it is a recent topic, there is not a diversity of studies available to compare the results obtained, which is corroborated as a limitation of this study. Thus, in view

of the decrease in cases of COVID-19 and the full return of activities and institutions attended by these children and adolescents, it is expected that, through this research, it will be thoroughly investigated how these impacts may have influenced the return of routine of these families.

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