






## ORIGINAL ARTICLE

## PSYCHOSOCIAL REPERCUSSIONS OF THE COVID-19 PANDEMIC FOR MOTHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER\*

### HIGHLIGHTS

1. The pandemic has disproportionately affected people with autism.
2. Emotions and behaviors of autistic people were difficult for their mothers.
3. Mothers experienced physical, emotional and psychological overload.
4. Feelings of helplessness and loneliness were exacerbated by the pandemic.

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### ABSTRACT

**Objective:** to understand the psychosocial repercussions of the COVID-19 pandemic for mothers of children with Autism Spectrum Disorder. **Method:** a qualitative study, with participation of 22 mothers. The data were collected from May to July 2022 in the inland of Paraíba, Brazil, through the Dynamics of Creativity and Sensitivity. The analysis took place through the theoretical-analytical framework of French discourse analysis. **Results:** fear, anxiety, anguish and concerns assumed a central place in the mothers' dialogical movement. Faced with the demands and reconfigurations in the routine, there was physical, emotional and psychological overload, with repercussions on maternal life. Loneliness can be seen in the weak or non-existent support network during the pandemic. **Conclusion:** the study can support reflection on the repercussions of the pandemic on the lives of mothers of children with autism and enable the development of actions that prioritize mental health, helping them to overcome moments of adversity.

**DESCRIPTORS:** Pandemic; COVID-19; Mothers; Autism Spectrum Disorder; Psychosocial Impact.

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## INTRODUCTION

During the COVID-19 critical period, especially in 2020 and 2021, almost the entire planet experienced a serious health, social, economic and humanitarian crisis, putting the human species to the test in several dimensions<sup>1</sup>. The disease caused by SARS-CoV-2 is considered a medical phenomenon when considering its etiology, as well as a social one, with a widespread effect on people's health and well-being<sup>2-3</sup>. The measures imposed to contain the pandemic were responsible for multiple changes and interruptions in various aspects of daily life, which generated feelings of tension, fear, stress and anxiety<sup>4-5</sup>.

Thinking about the particularities of people with disabilities, especially those with Autism Spectrum Disorder (ASD), raises reflections on how they have been and continue to be impacted by the pandemic<sup>6</sup>. This population group was disproportionately affected and had an impact on the mothers' well-being, as the possibilities that would favor development of their children were abruptly interrupted, causing harms to life, behaviors, and physical and mental health<sup>6-8</sup>.

Psychosocial factors that permeate social distancing, such as separation from family, social environment and school, or changes in the routine, triggered emotional and behavioral changes in people with ASD, which were difficult for mothers to manage<sup>9-10</sup>, who were already facing increased psychological, physical and emotional pressures, in addition to the need to reconcile different functions<sup>11-12</sup>. The overload experienced during the pandemic period had repercussions on these women's health, human relationships and social practices.

Upon entering the pandemic period, mothers had to deal with an unknown and distressing situation, which weakened future plans and made the possibility of death imminent, added to the daily challenges of caring for atypical children, which was not an easy task.

Although the COVID-19 pandemic and social isolation/distancing are topics that have been widely discussed in national and international journals in recent years, the emphasis has sometimes been placed on clinical-care aspects, relegating the sociocultural and psychological dimensions, and the approach to the topic with the experiences of mothers of children/adolescents with ASD is still underexploited.

Thinking about and discussing how mothers experienced this period can provide elements for the development of social assistance interventions aimed at maintaining or improving the quality of life and mental health of this population. In view of the above, the research objective was to understand the psychosocial repercussions of the COVID-19 pandemic for mothers of children with Autism Spectrum Disorder.

## METHOD

A qualitative study of the exploratory-descriptive type, based on the Consolidated Criteria for Reporting Qualitative Research (COREQ)<sup>13</sup>. The research was carried out in an Association of Parents and Friends of Autistic People, a reference for its pioneering spirit and relevance in the work developed for people with ASD and their families, located in the inland of Paraíba, Brazil.

The sample was for convenience, after an individual invitation made to the mothers by the president of the Association. After acceptance, the meetings were scheduled according to the participants' availability. It is noted that none of the invited women refused to participate in the research.

The following criteria were adopted for inclusion: being a mother of a child/adolescent with ASD; being at least 18 years old; participating in the Association's activities for a period longer than two years, which corresponds to the pandemic period; having a complete vaccination schedule against COVID-19. Those who were not attending the association during the data collection period for some reason and those who had flu-like symptoms were excluded.

The data were collected in May and July 2022, considering the data saturation point<sup>14</sup>, through the Dynamics of Creativity and Sensitivity (DCS) and by means of the Comic Book Technique (CBT), a playful strategy in which participants have the possibility of expressing themselves about a real situation they experience in their everyday lives, through analogies between pictures from comic book magazines<sup>15</sup>. The *Turma da Mônica* comic books were used, available in PDF and printed by the researcher.

The Association allocated a space in the institution itself for the development of group work and the moments were carried out exclusively by a single researcher, to minimize biases. The environment was organized so that the participants were comfortable, with enough space to move around and share experiences from a dialogical perspective. Furthermore, a recording and filming system was installed for the meetings.

The participants were divided into four groups on different days: two groups with five mothers and another two with six mothers, totaling 22 participants. To perform the technique, the mothers were instructed on the DCS stages. Subsequently, the comic books were made available upon request that, through one or more figures from the magazines, aspects regarding the following guiding phrase would be represented: "For me, the COVID-19 pandemic represented...". Subsequently, the participants discussed the pandemic period, making a connection with the chosen figure. Application of this method allowed dialogue between mothers with a mean duration of 58 minutes.

A pilot trial, which was later discarded, was carried out with the president of the Association to adapt the instrument. The data that emerged from the DCS were recorded, transcribed in full and made available to the participants to evaluate consistency of the testimonies, increasing reliability of the material.

The empirical material analysis was carried out according to the theoretical-analytical framework of French Discourse Analysis (DA). We started from the linguistic surface towards the discourse, building the discursive *corpus* – discursive excerpts from the narratives presented by the mothers and their association with the chosen comic book figure. After the first analysis step, the discursive object was constituted. Repeated readings of the *corpus* were carried out in a constant back-and-forth between theory and analysis, in search of understanding the meaning production processes. The analytical reading of the discursive object pointed out the clues indicating the analytical devices that constitute the participants' discourse<sup>16</sup>. Through the identification of paraphrastic, polysemic and metaphorical processes, the discursive formations were related, analyzing the statements that characterized the participants' testimonies regarding ideological stance, their relationship with other statements, networks of historical affiliations and interdiscourse.

The research was approved by the Research Ethics Committee with opinion No. 5,248,572. Anonymity and confidentiality of the information were preserved by identifying the mothers with the letter M, followed by an ordinal numeral (M1, M2, ..., M22).

## RESULTS

The analytical device was constructed through maternal narratives about the repercussions of the COVID-19 pandemic on their lives, the researchers' interpretation,

the theoretical framework and the conditions for producing the discourse. Two discursive formations were organized: Reality of mothers of children with ASD during the COVID-19 pandemic; and Maternal helplessness: absence of a support network.

The relationship between text and history, the marks of social and human transformations that build meaning over time, is important for DA. In this sense, the current analysis considers the discursive place of 22 women who spoke from a specific stance, as mothers of children with ASD and, as a result, their testimonies are full of regularities or linguistic clues, characteristics of this social place where it is stated from.

The participants' age group varied from 22 to 72 years old with a mean of 39. Slightly more than half (63%) are married or in a civil union. As for schooling, 59% have Complete High School; 82% earn family incomes of two minimum wages at the most; and 59% do not have continued employment, with exclusive dedication to caring for their children and their home.

### Reality of mothers of children with ASD during the COVID-19 pandemic

In the analysis task we listened to maternal statements about the experiences of encountering the reality of a pandemic period, the drama experienced and the meaning of this experience.

The direct coexistence with the possibility of death, the presence of distress, the surprise with the circumstances, the anguish and impotence to change the new situation and its limits in the face of what was to come, everything formed a statement that appears complex and establishes a break with the existential everyday life experienced until then.

The narratives indicate that feelings of fear, anxiety, anguish and concern assumed a central place in the mothers' dialogical movement, with negative consequences for physical, emotional and mental health. This can be evidenced in the discursive excerpts below:

*I was so afraid... // fear of the virus, of the disease, fear that terrifies me. (...) An aunt of mine passed away with COVID, look, it was a huge disaster for our family. (M5)*

*The worst part was the fear, right? The fear of getting infected and bringing it to my children and parents. So much loss for us during this period (...) there was my father-in-law and my aunt who passed away due to COVID and there was also his teacher [referring to her son with ASD]. It was very difficult! It was a difficult time, and I cried a lot. (M15)*

The feelings experienced by these women during the pandemic were represented by Figure 01, chosen by one of the participants.



**Figure 1.** Maternal feelings related to the COVID-19 pandemic. Fortaleza, CE, Brazil, 2022Source: Sousa (2004)<sup>17</sup>

*Girl, I'm going to choose this figure, because I'm all like this. I was afraid of everything // I was afraid of dying, of the boys dying [referring to children with ASD], my mental health was destroyed! I'm scared to death of leaving these boys... my anxiety attacks are just afraid of death; do you think there are people who want them [referring to children with ASD]??? Just me, girl! (M11)*

The overload of these women during the pandemic had repercussions on different aspects of their lives, as expressed in the following statements:

*I've always been alone to take care of a lot of things and also of the boys [referring to the children] // I get desperate to take care of everything. And during the pandemic it was even worse // It was a very distressed period // I almost went crazy! (M8)*

*I was very stressed, having to do everything alone. It's heavy, you know? I lead a life like this [crying] // overwhelmed (...) because it's just me for everything! Every load is on me. (M13)*

In addition to the feeling of loneliness, excessive demands and responsibilities can have consequences for these women's mental health. Chosen by one of the participants, Figure 2 depicts the impact of the pandemic on mental health.

**Figure 2.** Maternal overload during the COVID-19 pandemic and the consequences on mental health. Fortaleza, CE, Brazil, 2022Source: Sousa (2016)<sup>18</sup>

*I was so stressed, I wanted to kill someone [laughs]. This little figure is me wanting to kill people // In fact, I think I was crazy. [Son's name] was always at home, he would have crises, cry, and I didn't know what to do. Dividing the struggle at home, with [son's name], with work activities... // there was a time when I couldn't do it anymore, I felt sick. It was painful! (M1)*

The impact on these women's mental health was related to the need to balance professional and personal life, added to household chores, caring for children's demands, rigorous cleaning of everything and the constant fear of contamination.

Three participants did not choose any figure and stated that the pandemic period did not change their lives in any way; however, the circumstance indicated greater distress



and a drastic change in routines, as exemplified by one of the statements:

*Girl, I have no life. I was never one to go out, to have friends, so the pandemic period didn't change anything // I was already isolated from everything and everyone. So, given the life I have, I didn't find it so difficult (...) now, was I afraid of the disease? Of course I was. (M19)*

### Maternal helplessness: absence of a support network

A united and strengthened support network is one of the important pillars for mothers who have children with autism. The pandemic increased this need due to the diversity of roles played by women. Faced with so many demands and routine reconfiguration, mothers felt overwhelmed, needing tangible help in daily activities and caring for their children.

Most of the participants did not have a support network, and those who did considered it small and weak. The mothers talked about loneliness and helplessness in caring for their children and the emotional and mental consequences of this abandonment. The absence of a support network is a reality experienced by mothers since the discovery of their child's disorder, as observed below:

*I never had a support network; it wasn't just because of the pandemic. There are times when it comes to despair! I never had family support for anything, so everything stayed the same. (M10)*

*I don't have anyone to help me // My family is not understanding at all, they just say it's tantrums, lack of patience, that in the past they didn't have that, that if I beat [daughter's name] she'd behave well // I only get a lot of judgment (...). (M22)*

It was possible to perceive the marks of loneliness also in the choice of figures, as they illustrate women who are alone and/or only accompanied by their child. This causes a large emotional void, leads to isolation and depression and results in emotional disruption among these mothers, as seen in Figure 3.



**Figure 3.** Maternal helplessness during the COVID-19 pandemic. Fortaleza, CE, Brazil, 2022

Source: Sousa (2004)<sup>17</sup>

*My support network is [she mentions her own name four times] [laughs]. Everything is just me, always has been and certainly always will be (...). As long as I'm standing, it'll be like this (...). (M2)*

The striking presence of pauses, silences and tears in the narratives makes clear the difficulty defining the sentimental void and managing the scars caused by abandonment. Paternal absence in the mother/child care and life was configured as another abandonment side aspect and strongly determines the mothers' emotional evolution, as identified in the following testimonies:

*My husband doesn't spend a minute a day with [daughter's name]... do you know what a repellent is? It's as if she had a repellent and he couldn't or didn't want to get close to her. (...) I've suffered a lot from this, today I don't suffer anymore! (M2)*

*Their father [referring to the children] doesn't take care of us at all. He [ex-husband] left, got married again, and doesn't even care if we're alive. // Look, I try to be strong, but my emotional state is finished (...) My everyday life is heavy, I have no life, I feel frustrated [crying]. (M12)*

When put into words, the paternal abandonment tones are raw, painful and become a foundation that deteriorates maternal existence.

The similarity between the paths described lies in the mothers' loneliness and isolation when facing the reality of the condition of children with ASD alone or, sometimes, only with the help of the maternal family members, who are available to help with the child's demands, as observed:

*Woe to me if it wasn't for my family. Since the diagnosis, they've always been with me [crying]. The paternal family never did anything for us. The biggest contribution they made was questioning the diagnosis to the neuropediatrician, because they thought it was something I invented in my mind. (M15)*

Chosen by one of the participants, Figure 4 highlights the importance of the family as support not only during the pandemic period, but throughout life.



**Figure 4.** The maternal family as an important support network. Fortaleza, CE, Brazil, 2022  
Source: Sousa (2009)<sup>19</sup>

*My family helps a lot, it's strengthening having them around. If I didn't have so much support, I would've already gone mad. I don't see myself without my family, my aid, my*

*support network. If it's difficult for me having them, imagine if I didn't? Because I know I'm privileged, I know several mothers who don't have any support. Experiencing autism is not easy with family support, let alone without it. (M20)*

## DISCUSSION

The world population inserted in the pandemic scenario has suffered psychosocial impacts at different intensity and severity levels, but it is believed that the presence of a child with ASD has further aggravated the situation due to the difficulties they present adjusting to the changes and adaptations in the routine that were necessary due to the pandemic.

The different types of fear experienced by mothers during this period were something kept in the narrative, in memory, characterizing the paraphrase<sup>16</sup>. The fear experienced by the participants did not arise out of nowhere; it was socially constructed, triggered by a situation of permanent tension due to the possibility of exposure to the virus, the constant threat of illness and the proximity of death.

The high number of cases and deaths, all the information disseminated by the media and propagated through social networks, the lack of a specific antiviral treatment for the disease and false information regarding effectiveness of the vaccines contributed to generalizing fear regarding COVID-19<sup>20</sup>.

The significant fear of death expressed by M11 related to the perception of the children's vulnerability throughout their lives signals the existence of a statement linked to the repeatability effect, as formulations already stated hover in the interdiscourse<sup>21</sup>.

DA makes use of a combination of social, historical and cultural circumstances that influence the production of a given discourse<sup>16</sup>. In this sense, it is important to highlight that all participants directly experienced contamination by the coronavirus, whether through their own illness or through the illness of people close to them, deterioration of their health condition and/or loss of a family member or people they knew.

The pandemic has been associated with mass losses of both human lives and routines, face-to-face social connections and financial instability. The rapid changes in the population's daily lives and the need to deal with an extremely unpredictable future, in addition to so many infections and deaths, led people to experience feelings of extreme distress<sup>22</sup>.

Narratives related to work overload, anxiety and stress mark the interdiscourse, defined as what was said before, elsewhere. In addition to the emotional readjustment suffered by mothers of people with ASD during the pandemic, the accumulation of tasks and multiple functions was intense and brought about physical, psychological and emotional overload, increasing stress levels<sup>23-24</sup>.

Raising a child with some type of disability is associated with high parental tension under normal circumstances, and the drastic changes in the families' routines during the COVID-19 pandemic may have increased the risk of parents experiencing higher psychological distress levels<sup>25</sup>.

Discourses about loneliness and maternal isolation have already been stated and re-stated in other socio-historical contexts, due to the characteristics specific to the child's disorder, that is, they are in the order of interdiscourse that works with the repeatable; but these feelings have been exacerbated by the pandemic period.

The polysemy that is characterized by the displacement process, the cut in the meaning



processes and the misunderstanding in discourse<sup>21</sup> could be observed in the narrative which states that the pandemic did not change their life in any way. This statement reflects a stance of submission and nullity in these women's life, in which the priority is always the other. Considering the historicity of these mothers and valuing the senses in interaction with others, oftentimes in the order of interdiscourse, they have already found themselves nullified by society, by the care burden and by patriarchy.

Interdiscourse was also observed in the narratives that signal the discursive memory about the absence of a support network and loneliness in caring for the child that precedes, sustains and determines the statements they produce. The reality is that, from an in-depth perspective, most of the time, the mothers are the environment, the universe where the children's life takes place.

Based on a sociocultural construction, women see themselves as primarily responsible for caring for the family. Even faced with an intense demand for activities, they assume the role of caregivers, as they believe that survival of their children is the result of their dedication, seeking conditions for the development of this solitary and supportive care. For being solitary, this search constitutes a source of suffering and stress<sup>26</sup>.

Depending on the circumstances surrounding abandonment, mothers are forced to take on tasks, obligations or roles that they would not need to and/or should do alone. These facts were magnified during the pandemic, increasing female overload and potentiating physical and mental ailments.

Different forms of paternal abandonment were observed throughout the narratives: physically and psychologically absent fathers, who left the mothers alone in raising the children, withdrew from financial contributions and domestic tasks, and were not interested in what happened to the children/mothers; in addition to those who, despite being "present", emotionally abandoned their wives and children, simply limiting themselves to paying bills.

The presence of a disability favors abandonment by the fathers, causing the figure of care to become female – mothers, grandmothers, aunts – where they begin to be exclusively devoted to caring, preserving and ensuring that the children achieve optimal development, as close as possible to the expectations<sup>27</sup>.

Spouse support and quality of the marital relationship are of utmost importance for mothers in the process of dealing with stress. A good marital relationship and the relationship between the father and the child with ASD reduces stress during the pandemic and decreases the risk of maternal depression, acting as a buffer against stress factors related to caring for a child with ASD<sup>28</sup>.

Family support is essential for the adaptation and development process of both children with ASD and their mothers, as it is understood that the positive influence of family members on mothers and children allows them to feel accepted, welcomed and safe<sup>27</sup>.

The strong presence of the maternal family as support for these women and with the experiences of autistic disorder allows mothers greater resilience, even in the face of adverse and unexpected cultural and family contexts, such as a disability diagnosis.

It is noted that the socioeconomic context in which the study participants are inserted can influence their perceptions, making it impossible for the results presented to be generalized to other scenarios, an aspect that constitutes the limitation of this research.

## FINAL CONSIDERATIONS

The COVID-19 period exerted a strong impact on the lives of mothers of children

with ASD. It was identified that feelings of fear, stress, anxiety, overload, loneliness and helplessness were striking in the maternal narratives, although they did not only emerge during the pandemic period. This is a reality experienced throughout these women's lives, since their children's diagnosis and exacerbated during the aforementioned period.

An important aspect that should be considered is a way to prevent/reduce the feelings of "lack of support" and "helplessness" to mitigate burden on mothers. Availability of this information will help better meet the needs of mothers of individuals with ASD during future public health emergencies.

The results presented in this study can offer contributions to the mental health area, enabling actions within health care and social support programs for mothers of children with ASD, impacting the quality of life of this population group.

It is suggested that studies be carried out in other spaces, with different socioeconomic and cultural contexts, in order to trigger new discussions and research on the topic. However, the use of DCS and the comic book technique, as a strategy for data collection in qualitative research, allowed the participants to reflect and express in a group and spontaneous way the reality experienced during the pandemic through dialogue and interaction, configuring a study strength.

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Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - **Teixeira OFB, Rocha FL, Silva JWM da, Pessoa VLM de P, Miranda KCL.** Drafting the work or revising it critically for important intellectual content - **Teixeira OFB, Rocha FL, Silva JWM da, Pessoa VLM de P, Miranda KCL.** Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - **Teixeira OFB.** All authors approved the final version of the text.

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