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ORIGINAL ARTICLE

Comparative analysis between the mental health of responsible for people with ASD and for children without ASD in the COVID-19 pandemic

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Keywords:
Pandemic,
Autism Spectrum Disorder,
Mental Health,
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Abstract

Objectives: To compare the quality of mental health of those responsible for people with autism spectrum disorder (ASD) and those responsible for people up to 12 years old without autism during the COVID-19 pandemic, with regard to symptoms of different levels of depression, anxiety, and stress and find associations between these levels with psychosocial and economic variables. **Methods:** It was a cross-sectional, observational, and quantitative study, which analyzed an online form with the DASS-21 scale and with questions regarding the psychosocial and economic characterization of residents of the municipalities in the south of the state of Rio de Janeiro during the COVID-19 pandemic. The disclosure took place through social networks and the data obtained were tabulated using Microsoft Excel 2016 software. **Results:** 77 people participated in the study, divided into 2 groups: group A, of those responsible for people with ASD, totaled 30 people and group B, of those responsible for children without ASD up to 12 years old, 47 people. From group A, 60% had symptoms of depression, 76.67% with symptoms of anxiety, and 80% with symptoms of stress. In group B, 44.68% had symptoms of depression, 46.81% with symptoms of anxiety, and 70.21% with symptoms of stress. **Conclusions:** The results of this research address the need for interventions to prevent these disorders and the psychological support of this population, with the inclusion of the family nucleus in the therapeutic planning of people with autism and assistance in the development of crisis coping strategies, as in the current scenario.

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INTRODUCTION

Autism Spectrum Disorder (ASD) brings together neurological development disorders present from birth or early childhood, which can affect social communication, social interaction and restricted and repetitive patterns of behavior[1]. In the United States, one in every 54 children has this disorder, a significant number that highlights the need to develop public policies for this population[2].

Among the various manifestations of autism, we list social isolation, repetitive routines and behaviors, inappropriate laughter, difficulty in communication, lack of eye contact, echolalia, resistance to physical contact and self-aggression, behaviors that present themselves daily at different intensities[3]. Dealing with these emotional reactions and behavioral changes is not always easy for family members or caregivers, as it requires daily dynamism. They often report a physical and mental burden due to the great demand for care that a child with ASD requires, and changes to the family's routine, such as habits, financial expenses, social and professional relationships, which can be perceived as event stressors[4].

A systematic review highlighted that emotional burden is one of the main challenges faced by families that live with children with ASD[5]. A study involving the parents of these children found that 68% of their sample are unable to have a life independent from their children, leaving leisure situations and social relationships quite restricted. They also highlighted that the most important factors causing stress are the poor acceptance of autistic behaviors by society and other family members, increased financial demand, lack of social and communication support, children's behavior and daily activities[6]. An observational study carried out in the United Kingdom found that family members and caregivers of children with ASD manifest high levels of stress when compared to families of children with typical development[7]. The authors of these studies also point out the isolation due to the children's difficulty in adapting, the severity of autistic symptoms, the difficulty in accessing healthcare services and the buildup of economic difficulties faced, as significant factors for the stress increase in these caregivers[6,7]. The guardians feel alone in this care process, which can lead to stress, depression and anxiety, and its levels are higher in families with autism than in those with individuals with other diseases[3].

A study that examined the longitudinal associations between child behavior problems, coping strategies, social resources and parental stress in mothers of children with ASD found that the level of stress is related to the quality of social support provided to those involved in child rearing, where the social support available is extremely important[8]. In this context, various services are included, such as specialized early childhood education, which, according to a study carried out with 30 autistic mothers and children in Porto Alegre, has a protective function for those caregivers, offering information and guidance, psychological support and groups of parents[9]. Regarding support networks, an integrative review described that most children receive assistance from associations such as AMA (Association of Friends of the Autist), APAE (Association of Parents and Friends of the Exceptional) and CAPSi (Child Psychosocial Care Center), with a psychologist, speech therapist, psychological-pedagogist, neurologist and occupational therapist[10]. However, there is always parental burden, even with a support network, which in many municipalities is not yet comprehensive. A qualitative research carried out with families cared for by 14 CAPSi in the metropolitan region of Rio de Janeiro found that this is due to the exhausting daily life of commuting between the mentioned places of treatment for autistic people due to the fragmentation of care[11]. This reality negatively affects the mental health of caregivers, who abdicate their leisure and personal care, which demonstrates the need for interventions that take into account the entire family unit[3].

Even so, support networks are directly related to family and, therefore, child development. In this context, the distancing of these services negatively affects the learning process of these children. The COVID-19 pandemic and the need for social isolation as a disease prevention measure caused a drastic change in the routine of these families. The care that was previously shared with the support network has now become the exclusive responsibility of these caregivers, requiring a reinvention of the family routine due to the drastic changes in the national scenario. With that, new stressors came to play, such as overload of domestic activities, working outside the home or even indoors, as well as the children's demands (carrying out remote school activities, care and leisure activities), in addition to little or no space to be alone or carry out activities that one enjoys. The caregivers are then in a situation of vulnerability that can cause higher levels of depression, anxiety and stress, whose symptoms were already frequently manifested by this population outside the pandemic[12]. The aim of the study was to compare the quality of mental health of caregivers/guardians of children with ASD and caregivers of children up to 12 years of age without ASD, residing in municipalities in the south of the state of Rio de Janeiro during the COVID-19 pandemic, with regards to symptoms of different levels of depression, anxiety and stress, and finding associations between these levels with psychosocial and economic variables.

METHODS

This was a cross-sectional, observational, quantitative study that aimed to assess caregivers' symptoms in relation to different levels of depression, anxiety and stress, using the DASS-21 (Depression Anxiety Stress Scales). Studies show that the DASS, both in its original 42-item version and in its short 21-item version, is an effective and reliable instrument for detecting depression, anxiety and stress in adults[13]. In the online questionnaires, participants indicated the intensity and frequency of the experience reported in each of the items

during the previous week on a 4-point Likert-type scale, between 0 (not applicable to me) and 3 (very applicable to me, or most of the time). Scores for depression, anxiety and stress are determined by adding up the scores of the 21 items.

We used an electronic form, consisting of DASS-21 and questions regarding the psychosocial and economic characterization of the sample, through Google Forms (available at https://forms.gle/ShRbKPLDBn9SrRYv9). We distributed the forms through the virtual social networks: Facebook, Instagram, WhatsApp and email, sending objective messages and with the support of key users, in order to encourage compliance and distribute the questionnaires. We plotted the data found on Google Docs platform, and later analyzed with the help of Microsoft Excel 2016 software.

For comparison purposes, we analyzed the data by dividing the sample into two groups, whose members should be adults living in cities in the south of the state of Rio de Janeiro and living in social isolation. In group A, caregivers of children with ASD were included, and in group B, caregivers of children up to 12 years old without ASD. To access the questionnaires, a login on the Google platform was required, ensuring that the answers were not duplicated. The participant had to agree with the Informed Consent Form (FICF), confirming that they were aware of the term's content and agreeing to participate anonymously in this study. This application format did not allow personal feedback regarding disorders analyzed in this study, despite the effectiveness and reliability of the tool used for detection. However, the researchers' contacts were made available to all participants, so that doubts could be clarified, including the perception of the need for healthcare referrals.

This paper was submitted to the Ethics Committee for Research on Human Beings at the Oswaldo Aranha Foundation, in the municipality of Volta Redonda, in the state of Rio de Janeiro and was approved under number CAAE 34903220.3.0000.5237.

RESULTS AND DISCUSSION

This study enrolled 77 caregivers, divided into 2 groups for better data analysis. Group A, those caring for people with ASD, totaled 30 people; and group B, those caring for children up to 12 years old without ASD, 47 people. The analysis of the profile of all guardians revealed that most of them are cisgender women (90.90%), white (64.93%), married (70.12%), residents of the municipality of Volta Redonda (71.43%), with a monthly family income of 3 to 6 minimum wages (27.27%) and are not responsible for another person with a diagnosed chronic illness or mental illness (81.82%).

Regarding the care of children, 43.33% of those responsible for group A indicated that they received help from family members, caregivers or others, with 46.15% depending little, 38.46% highly dependent and 15.38% totally dependent on this aid. In group B, 55.31% of the guardians indicated that they received this assistance, and 34.61% depend little, 53.84% depend a lot and 11.53% totally depend on it. When asked about the continuity of this aid during the pandemic, 46.15% of group A indicated that they continued receiving help normally, 38.46% that they continued receiving it partially, and 15.38% that they stopped receiving it completely; while in group B, 34, 61% continued to receive it normally, 42.30% continued partially and 23.07% stopped receiving aid altogether.

There was no significant difference regarding the establishment of a new routine in the midst of the pandemic between the two groups, and in both, about 70% of the individuals managed to establish it at least partially.

The present study found that all those caring for group A and their families were inserted in support networks, in agreement with an integrative review that found that most children receive assistance from associations such as AMA, APAE and CAPSi, with a psychologist , speech therapist, psychopedagogist, neurologist and occupational therapist[10]. Regarding the financing of these services, it is fully paid by 28% of the families, partially paid by 32% of them and fully public in 40% of them. Five questionnaires were excluded from the analysis of this category due to incompatibility in the marking of responses.

Professionals included in the routine of these families were: Pediatrician and/or Neuropediatrician (20 responses), Regular school (18 responses), Speech therapist (16 responses), Occupational therapist (15 responses), Psychologist (14 responses), Basic Health Unit (11 answers), Psychiatrist (10 answers), Specialized school (9 answers) and Physiotherapist (7 answers). Other professionals and therapies were mentioned by those in care: Nutritionist, Psychopedagogist, Specialized Dentist, Hippotherapy, ABA Therapy (Applied Behavior Analysis), Dance and Multifunctional resource room. When asked about the professionals who continued to provide support during the pandemic, there was an overall reduction in responses, especially for Pediatricians and/or Neuropediatricians, with a drop of 55%.

We found that both groups felt overloaded during the pandemic, with similar numbers: only one individual from each of them marked that they felt overloaded, and more than half indicated that they felt very overloaded, which corresponds to 56.66% in group A and 55.31% in group B. This reveals that the physical and mental overload referred to with recurrence by those caring for children with ASD may have been fundamental for the two groups to be affected in a similar way, since this reality, previously described in the literature, reflects the resilience potential of these families to changes in their family routine.

The factors that had the highest impact were: social isolation (44 responses), household activities (36 responses), remote school activities for the children (36 responses), child care activities - such as hygiene and feeding (15 responses), activities from work (15 responses), not being able to stay at home because of work or for any other reason (15 responses) and fear of losing a job or being unemployed (11 responses).

Another factor brought by the sample in this questioning was the lack of privacy, which was also assessed in the

survey. About this, this study found that 82.97% of group B marked that the time available to be alone and/or do activities that they enjoy with peace of mind decreased, while in group A, 80% of guardians marked this response. This issue is recurrent among parents of people with ASD since before the pandemic: one study found that 68% of its sample are unable to have a life independent of their children, leaving leisure situations and social relationships quite restricted, and highlighted isolation as a significant factor for increased stress among guardians and caregivers[6].

However, when asked about the intensification of family life, the caregivers were not very bothered in general; with group B being feeling more affected than group A: 46.66% of group A said they were not bothered at all, while 59.57% of group B marked this alternative. No participant in group A marked that they felt very uncomfortable and only 4.25% of group B marked this alternative.

About the pandemic having negatively affected the mental health of the caregivers, only 6.66% of group A marked that it did not affect at all, while 8.51% of group B marked this alternative. There was a small difference between the groups when analyzing the very much and medium alternatives together: 76.66% of group A and 68.08% of group B answered in this way.

In relation to having some professional psychological support or support group/therapy, less than half of both groups marked the alternative yes: 40% in group A and 23.40% in group B. A is the group with the highest psychological support; it may be because it is entirely inserted in support networks. However, during the pandemic, half of group A lost access to this support and only 1 caregiver maintained it normally, while 81.81% of group B maintained this access partially or normally. This finding reflects the negative interferences of the pandemic in the family routine of group A, whose guardians often give up their personal pleasures and mental health self-care in favor of adapting and caring for their children.

The pandemic scenario required major changes within the routine of those responsible for people with ASD, a population that even outside this context often manifests symptoms of depression, anxiety and stress[12]. Group A was the most affected with symptoms of depression, with 60% of the sample affected and of those, half with severe or extremely severe symptoms. 44.68% of group B, in turn, were affected, with the rate of mild symptoms being the highest found, 17.02%.

Group A was the most affected with anxiety symptoms, with 76.67% of its parents/guardians affected, while group B had an index of 46.81%. In addition, half of the first group manifested severe or extremely severe anxiety symptoms. On the other hand, the highest percentage found in group B was of guardians categorized as normal, corresponding to more than half of their sample (53.19%).

Regarding stress, the survey revealed that approximately 57 people (74%) had some degree of stress symptoms, corresponding to 80% of Group A and 70.21% of Group B. These data are in accordance with the study carried out in the United Kingdom, which reported that family members and caregivers of children with ASD manifest high levels of stress when compared to families of children with normal development[7].

CONCLUSION

Group A was more affected than group B, with more than half of its sample manifesting symptoms of the three disorders. Half of the guardians had symptoms of extremely severe or severe anxiety and stress and extremely severe, severe or moderate depression. In group B, more than half were normal when analyzing symptoms of anxiety and depression and, when analyzing stress, it was found that the highest rate was mild stress symptoms, around 21%.

The results of this study point to the need for interventions aimed at preventing these disorders and providing psychological support for this population, with the inclusion of the family nucleus in the therapeutic planning of people with Autism and assistance in the development of crisis-coping strategies, such as the current scenario. Therefore, it is essential to maintain the accessibility of communication channels, in addition to the interdisciplinary effort of the team involved in the treatment of these people to accommodate the special demands of each family, monitoring cases of greater vulnerability, recognizing their socioeconomic and psychosocial reality and accommodating their specific demands, respecting the sanitary safety measures in force. In addition, this study reveals the need to continue the development of research on the mental health of those caring for people with ASD, in order to expand knowledge about the impacts of this disorder on the family group, bringing about progress in the struggle for the right to mental health in these families.

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Responsible parties - Depression, Anxiety and Stress (DASS21) and COVID-19

You are being invited to participate in a survey that aims to

to compare the mental health quality of guardians of people with Autism Spectrum Disorder (ASD) and guardians of children without ASD living in municipalities in the southern state of Rio de Janeiro during the COVID-19 pandemic.

THE QUESTIONNAIRE SEEMS LONG, BUT THE ESTIMATED TIME TO COMPLETE IS 5 MINUTES ONLY. ALL ANSWERS ARE VERY IMPORTANT TO THE SURVEY. ONLY ONE RESPONSIBLE PER FAMILY SHOULD RESPOND

You must answer this questionnaire only once and may refuse to participate in the survey and may abandon the procedure at any time, without any penalty or loss. During the application and completion of the questionnaire, you may refuse to answer any question that may cause you any embarrassment.

Your participation as a volunteer will not gain any privileges, whether financial or of any kind, and you may withdraw from the project at any time without any harm to you.

Your participation will involve minimal risks, including donating your time to answer the proposed questionnaire.

Secrecy and privacy will be guaranteed, with the participant having the right to omit their identification or data that could compromise them. No data regarding your login to your Google account or your IP (internet protocol) will be stored or even made available to researchers at any time during the research or after it.

In the presentation of the results, personal data of the participants will not be mentioned. This work was approved by the research ethics committee under no. CAAE 34903220.3.0000.5237

Project Coordinator: Clarisse Pereira D. D. Fortes

Project Coordinator contact numbers: (24) 98824-9606

Address of the Research Ethics Committee: Avenida Paulo Erlei Alves Abrantes, 1325 – Três Poços – Volta Redonda/ RJ

*Mandatory.

1. E-mail *

After reading the description of this project:*

2. Mark only one oval.

( ) I confirm that I am aware of the content of this term, I agree to participate in this research and, therefore, I give my consent.

3. How many children do you have (and live with you)?*

Mark only one oval.

( ) 0
( ) 1
( ) 2
( ) 3
( ) 4
5 or more
Other: _____

4. How many of them are children (up to 12 years old)?*

Mark only one oval.

( ) 0
( ) 1
( ) 2
( ) 3
( ) 4
( ) 5 or more
Other: _____

5. How many children diagnosed with Autism Spectrum Disorder (ASD) do you have (and live with you)? *
Mark only one oval.

( ) I do NOT have a child diagnosed with ASD.
( ) 1
( ) 2
( ) 3
( ) 4
( ) 5 or more
Other: _____

6. Are you responsible for someone else who has a diagnosed chronic illness or mental illness?*
Mark only one oval.

( ) No *Skip to question 57.*
( ) Yes *Skip to question 56.*

7. After reading the description of this project:*
Mark only one oval.

( ) I confirm to have knowledge of the content of this term, I agree to participate in this research and, for that, I give my consent.

8. How many children do you have (and live with you)?*
Mark only one oval.

( ) 0
( ) 1
( ) 2
( ) 3
( ) 4
( ) 5 or more
( ) Other: _____

9. How many of them are children (up to 12 years old)?*
Mark only one oval.

( ) 0
( ) 1
( ) 2
( ) 3
( ) 4
( ) 5 or more
Other: _____

10. How many children diagnosed with Autism Spectrum Disorder (ASD) do you have (and live with you)?*
Mark only one oval.

( ) I do NOT have a child diagnosed with ASD.
( ) 1
( ) 2
( ) 3
( ) 4
( ) 5 or more
Other: _____

11. Are you responsible for someone else who has a diagnosed chronic illness or mental illness?*
Mark only one oval.

( ) No
( ) Yes

12. Which disease?*
_____
_____
_____
_____

13. In which municipality in the south of RJ do you live? *
Mark only one oval.

( ) Angra dos Reis
( ) Barra do Piraí
( ) Barra Mansa
( ) Comendador Levy Gasparian
( )Engenheiro Paulo de Frontin
( ) Itatiaia
( ) Mendes
( ) Miguel Pereira
( ) Paracambi Paraíba do Sul
( ) Paraty
( ) Paty do Alferes
( ) Pinheiral
( ) Piraí
( ) Porto Real
( ) Quatis
( ) Resende
( ) Rio Claro
( ) Rio das Flores
( ) Sapucaia
( ) Três Rios
( ) Valença
( ) Vassouras
( ) Volta Redonda
Other: _____

14. What is your birth date? *
_____
Example: January 7, 2019

15. Considering the color classification established by the Brazilian Institute of Geography and Statistics (IBGE), how do you define yourself?*
Mark only one oval.

15. White
( ) Black
( )Yellow
( ) Indigenous

16. What gender do you identify with?*
Mark only one oval.

( ) Woman Cis (if identified with sex that was born)
( ) Woman Trans (not to identify with sex that was born)
( ) Man Cis (if identified with sex that was born)
( ) Trans Man (does not identify with the sex he was born)
Other: _____

17. What is your marital status?*
Mark only one oval.

( ) Married
( )Single
( ) Divorced/separated
( ) United, lives together
( ) Widowed

18. Adding your income to the income of the people who live with you, approximately how much is the monthly household income?*
Mark only one oval.

( ) No income
( ) Up to 1 minimum wage (up to R$1,045.00)
( ) From 1 to 3 minimum wages (from R$1,045.00 to R$3,135.00)
( ) From 3 to 6 minimum wages (from R$3,135.00 to R$6,270.00)
( ) From 6 to 9 minimum wages (from R$6,270.00 to R$9,405.00)
( ) From 9 to 12 minimum wages (from R$ 9,405.00 to R$ 12,540.00)
( ) More than 12 minimum wages (more than BRL 12,540.00)
( ) I prefer not to answer
Other: _____

19. Who resides with you besides your children?*
Mark only one oval.

( ) His father/mother.
( ) His grandparents.
( ) His uncles.

Other: _____

20. You are responsible for taking care of how many people in your home?*
Mark only one oval.

( ) 0
( ) 1
( ) 2
( ) 3
( ) 4
( ) 5 or more
( ) Other: _____

21. Do you normally receive help from family members, caregivers or others in caring for your children?*
Mark only one oval.

( ) Yes
( ) No

22. How much do you depend on this assistance? *
Mark only one oval.

 I don't have assistance
 I depend a little
 I depend a lot
 I totally depend

23. These people continued to help you during the pandemic?*
Mark only one oval.

 Did not have assistance
 Yes, normally
 Yes, partially
 No, they totally stopped

24. The financing of the support network in which you are inserted is: (consider as a support network a group of professionals who help in the treatment and care of the person with ASD)*
Mark only one oval.

 NOT have child with diagnosis of ASD
 There are inserted in any network of support Fully public
 Partially paid
 Fully paid

25. Usually, which of the professionals/entities listed below are included in the routine of the person with ASD? Check one or more*
Check all that are applicable.

 NOT have child with diagnosis of ASD
 Unit Basic of Health
 School regular
 School specializing
 Psychologist
 Psychiatrist
 Pediatrician and/or neuropediatrician Speech therapist
 Physiotherapist
 Occupational therapist

Other: _____

26. Which ones did you continue to receive support from during the pandemic? Check one or more.*
Check all that are applicable.

 NOT have child with diagnosis of ASD
Unit Basic of Health
 School regular
 School specializing
 Psychologist
 Psychiatrist
 Pediatrician and/or neuropediatrician Speech therapist
 Physiotherapist
 Occupational therapist
Other: _____

27. How overwhelmed are you feeling in this pandemic?*
Mark only one oval.

 Not
 at all
 A little
 Medium
 A lot

28. Which of these activities do you feel have bothered you the most? Check one or more.*
Check all that are applicable.

 Domestic activities
 Social isolation
 Realization of activities school to the distance of their children Activities of care of their children (hygiene, food, etc.)
 Activities of the work
 Not able to stay at home for because of work or other
 Fear of losing your job or being unemployed
 No
Other: _____

29. Has the time available to be alone and/or carry out activities you enjoy calmly decreased?*
Mark only one oval.

 Yes
 No

30. How much does the intensification of family life bother you?*
Mark only one oval.

 Not at all
 A little
 Medium
 A lot

31. Did you manage to establish a new routine in your home with the pandemic (having a time to wake up, eat meals and sleep)?*
Mark only one oval.

 Yes, totally
 Yes, partially
 No

32. How much do you think the pandemic has negatively affected your mental health (because of fear of your illness/ death or of those close to you, anguish, loneliness, etc)?*
Mark only one oval.

 Not att all
 A little
 Medium
 A lot

33. Do you usually have any professional psychological support or support group/therapy wheel?*
Mark only one oval l.

□ Yes
□ No

34. If so, do you still have access to this support during the pandemic? *
Mark only one oval.

□ Didn't have it before the pandemic
□ Yes, normally
□ Yes, partially
□ No

INSTRUCTIONS TO CONTINUE

Please carefully read each of the statements below and tick the appropriate number 0, 1, 2 or 3 that indicates how much it applied to you during the LAST WEEK, as indicated below:

0 Not applied at all
1 Applied to some degree, or for a short time
2 Applied to a considerable degree, or for a good part of the time
3 Applied a lot, or most of the time

35. I found it difficult to calm down.*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

36. My mouth felt dry.*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

37. I couldn't experience any positive feelings.*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

38. I had difficulty breathing at times (eg wheezing, shortness of breath, without making any physical effort).*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

39. I found it difficult to have the initiative to do things.*
Mark only one oval.

0 1 2 3

_____

□ □ □ □

_____

40. I had a tendency to overreact to situations.*
Mark only one oval.

0 1 2 3

_____

□ □ □ □

_____

41. I felt tremors (eg in my hands).*
Mark only one oval.

0 1 2 3

_____

□ □ □ □

_____

42. I felt I was always nervous.*
Mark only one oval

0 1 2 3

_____

□ □ □ □

_____

43. I worried about situations where I might panic and look ridiculous.*
Mark only one oval

0 1 2 3

_____

□ □ □ □

_____

44. I felt I had nothing to want.*
Mark only one oval

0 1 2 3

_____

□ □ □ □

_____

45. I felt agitated.*
Mark only one oval

0 1 2 3

_____

□ □ □ □

_____

46. I found it hard to relax.*
Mark only one oval

0 1 2 3

47. I felt depressed and discouraged.*
Mark only one oval

0 1 2 3

48. I was intolerant of the things that kept me from continuing what I was doing.*
Mark only one oval

0 1 2 3

49. I felt like I was going to panic.*
Mark only one oval

0 1 2 3

50. I couldn't get excited about anything.*
Mark only one oval

0 1 2 3

51. I felt I had no value as a person. *
Mark only one oval

0 1 2 3

52. I felt I was a little too emotional/sensitive.*
Mark only one oval

0 1 2 3

53. I knew my heart was altered even though I hadn't made any physical effort (eg, increased heart rate, cardiac dysrhythmia).*
Mark only one oval

0 1 2 3

_____

□ □ □ □

_____

54. I felt fearless for no reason.*
Mark only one oval

0 1 2 3

_____

□ □ □ □

_____

55. I felt that life was meaningless.*
Mark only one oval

0 1 2 3

_____

□ □ □ □

_____

56. Which disease?*

_____
_____
_____
_____
_____

57. In which municipality in the south of RJ do you live?*
Mark only one oval

□ Angra dos Reis
□ Barra do Piraí
□ Barra Mansa
□ Comendador Levy GasparianEngenheiro Paulo de Frontin Itatiaia
□ Mendes Miguel Pereira
□ Paracambi
□ Paraíba do SulParaty
□ Paty do AlferesPinheiral
□ Piraí Porto RealQuatis Resende Rio Claro
□ Rio das FloresSapucaia
□ Três Rios Valença Vassouras Volta Redonda
□ Other: _____

58. What is your date of birth?*

_____
Example: January 7, 2019

59. Considering the color classification established by the Brazilian Institute of Geography and Statistics (IBGE), how do you define yourself?*
Mark only one oval.

□ White
□ Black

□ Yellow
□ Indigenous

60. Which gender do you identify with?*
Mark only one oval.

□ Woman Cis (if identified with sex that was born)
□ Woman Trans (not to identify with sex that was born) Man Cis (if identified with sex that was born)
□ Trans Man (does not identify with the sex he was born)
Other: _____

61. What is your marital status?*
Mark only one oval.

□ Married Single
□ Divorced/separated
□ United, lives together
□ Widowed

62. Adding to his income with the income of people who live with you, as is approximately the income family monthly?*
Mark only one oval.

□ No income
□ Up to 1 minimum wage (up to R$1,045.00)
□ From 1 to 3 minimum wages (from R$1,045.00 to R$3,135.00)
□ From 3 to 6 minimum wages (from R$3,135.00 to R$6,270.00)
□ From 6 to 9 minimum wages (from R$6,270.00 to R $ $9,405.00)
□ From 9 to 12 minimum wages (from BRL 9,405.00 to BRL 12,540.00)
□More than 12 minimum wages (more than BRL 12,540.00)
I prefer not to answer
Other: _____

63. Who lives with you, apart from your children?*
Mark only one oval.

□ Father / Mother
□ His Grandparents
□ His Uncles
□ Other: _____

64. You are responsible for taking care of how many people in your home?*
Mark only one oval.

□ 0
□ 1
□ 2
□ 3
□ 4
□ 5 or more
□ Other: _____

65. Do you normally receive help from family members, caregivers or others in caring for your children?*
Mark only one oval.

□ Yes
□ No

66. How much do you depend on this help?*
Mark only one oval.

□ I don't have assistance
□ I depend a little
□ I depend a lot
□ I totally depend

67. Did these people continue to help you during the pandemic??*
Mark only one oval.

□ Did not have assistance
□ Yes, normally
□ Yes, partially
□ No, they totally stopped

68. The financing of the network of support in which you are placed is: (consider as a network of support one set of professionals that assist in the treatment and care of people with ASD)*
Mark only one oval.

□ NOT have child with diagnosis of ASD
□ There are inserted in any network of support
□ Fully public
□ Partially paid
□ Fully paid

69. Usually, which of the professionals/entities listed below are included in the routine of the person with ASD? Check one or more*
Check all that are applicable.

□ NOT have child with diagnosis of ASD
□Unit Basic of Health
□ School regular
□ School specializing
□ Psychologist
□ Psychiatrist
□ Pediatrician and/or neuropediatrician Speech therapist
□ Physiotherapist
□ Occupational therapist
Other: _____

70. Which ones did you continue to receive support from during the pandemic?
Check one or more *
Check all that apply.

□ NOT have child with diagnosis of ASD
□ Unit Basic of Health
□ School regular
□ School specializing
□ Psychologist
□ Psychiatrist

□ Pediatrician and/or neuropediatrician Speech therapist
□ Physiotherapist
□ Occupational therapist
□ Outro: _____

71. The how overwhelmed (a) you are to feeling this pandemic?*
Mark only one oval.

□ Not at all
□ A little
□ Medium
□ A lot

72. Which of these activities you think you have you bothered more? Check one or more*
Mark only one oval.

□ Domestic activities
□ Social isolation
□ Realization of activities school to the distance of their children Activities of care of their children (hygiene, food, etc.)
□ Activities of the work
□ Not able to stay at home for because of work or other Fear of losing your job or being unemployed
□ No
□ Other: _____

73. The time available for stand alone and / or perform activities that likes to calm down?*
Mark only one oval.

□ Yes
□ No

74. How much does the intensification of family life bother you ?*
Mark only one oval.

□ Not at all
□ A little
□ Medium
□ A lot

75. You could establish one new routine in your home with the pandemic (have one time to wake up, to the meals and sleep)?*
Mark only one oval.

□ Yes, totally,
□ Yes, partially
□ No

76. As you think that the pandemic has affected negatively to their health mental (the fear of illness / death her or from people nearby, anxiety, loneliness, etc.)?*
Mark only one oval.

□ Not at all
□ A little
□ Medium
□ A lot

77. Normally, you have some support psychological professional or group of support / wheel of therapy?*
Mark only one oval.

□ Yes
□ No

78. If so, do you still have access to this support during the pandemic?*
Mark only one oval.

□ Didn't have it before the pandemic
□ Yes, normally
□ Yes, partially
□ No

INSTRUCTIONS TO CONTINUE

By Please read carefully each one of the statements below and check the number appropriate 0, 1, 2 or 3 which indicate the as it is applied to you during the LAST WEEK, as the indication the following:

0 not be applied in way some
1 was applied in some degree, or a bit of time
2 was applied, in one degree considerably, or by one good part of the time
3 was applied much, or in most of the time

79. I found it difficult to calm down.*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

80. My mouth felt dry*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

81. I couldn't experience any positive feelings.*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

82. I had difficulty breathing at times (eg wheezing, shortness of breath, without making any physical effort).*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

83. I found it difficult to have the initiative to get things done.*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

84. I had a tendency to overreact to situations.*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

85. I felt tremors (eg in my hands).*
Mark only one oval.

Marcar apenas uma oval.
0 1 2 3
_____
□ □ □ □
_____

86. I felt like I was always nervous.*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

87. I worried about situations where I might panic and look ridiculous.*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

88. I felt I had nothing to want.*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

89. I felt agitated.*
Mark only one oval.

0 1 2 3

90. I found it difficult to relax.*
Mark only one oval.

0 1 2 3

91. I felt depressed and discouraged.*
Mark only one oval.

0 1 2 3

92. I was intolerant of the things that kept me from continuing what I was doing.*
Mark only one oval.

0 1 2 3

93. I felt like I was going to panic.*
Mark only one oval.

0 1 2 3

94. I couldn't get excited about anything.*
Mark only one oval.

0 1 2 3

95. I felt I had no value as a person.*
Mark only one oval.

0 1 2 3

96. I felt I was a little too emotional/sensitive. *
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

97 I knew that my heart was altered even though I didn't make any physical effort (eg increased heart rate, cardiac dysrhythmia).*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

98. I felt fearless for no reason.*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____

99. I felt that life was meaningless.*
Mark only one oval.

0 1 2 3
_____
□ □ □ □
_____