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Repercussions of COVID-19 for children and adolescents with Autism Spectrum Disorder and their families

Repercussões da COVID-19 para crianças e adolescentes com Transtorno do Espectro Autista e seus familiares

Repercusiones del COVID-19 para niños y adolescentes con Trastorno del Espectro Autista y sus familiares

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Objective: to verify the repercussion of social isolation for families with children and adolescents with Autism Spectrum Disorder. **Methods:** qualitative study with longitudinal follow-up, of an exploratory-descriptive nature, carried out in 2020, based on a semi-structured online questionnaire, carried out in three phases. Data were interpreted by thematic content analysis. **Results:** the first phase had 30 participants, the second with 10 and the third six, with at least one child diagnosed with the disorder, all male. From the thematic content analysis, the following categories emerged: "*Challenges of atypical motherhood and COVID-19*"; "*ASD in times of coronavirus: (self) regulation strategies*" AND "*Uncertainties about the future*". **Conclusion:** in the current pandemic context experienced, the family routine of autistic people presented changes with possible damage to the mental health of all those involved in the care. These findings point to the need to formulate strategies aimed at well-being and minimizing impacts on these people's family routine.

Descriptors: Autism Spectrum Disorder; COVID 19; Mental health; Psychosocial impact.

Objetivo: verificar a repercussão do isolamento social para famílias com crianças e adolescentes com Transtorno do Espectro Autista. **Método**: estudo qualitativo com seguimento longitudinal, de caráter exploratório-descritivo, realizado em 2020, a partir de um questionário *online* semi-estruturado, realizado em três fases. Os dados foram interpretados pela análise de conteúdo temática. **Resultados**: a primeira fase contou com 30 participantes, a segunda com 10 e a terceira seis, tendo pelo menos um filho diagnosticado com o transtorno, todos do sexo masculino. A partir da análise de conteúdo temática, emergiram as seguintes categorias: "*Desafios da maternidade atípica e a COVID-19*"; "*TEA em tempos de coronavírus: estratégias de (auto) regulação*" E "*Incertezas sobre o futuro*". **Conclusão**: no atual contexto pandêmico vivenciado, a rotina familiar de pessoas autistas apresentou alterações com possíveis prejuízos à saúde mental de todos os envolvidos no cuidado. Esses achados apontam a necessidade da formulação de estratégias que visem o bem-estar e minimizar os impactos no cotidiano familiar dessas pessoas.

Descritores: Transtorno do Espectro Autista; COVID-19; Saúde mental; Impacto psicossocial.

Objetivo: verificar las repercusiones del aislamiento social en las familias con niños y adolescentes con Trastorno del Espectro Autista. **Método:** estudio cualitativo con seguimiento longitudinal, de carácter exploratorio-descriptivo, realizado en 2020, a partir de un cuestionario online semi-estruturado, realizado en tres fases. Los datos se interpretaron mediante un análisis de contenido temático. **Resultados**: la primera fase contó con 30 participantes, la segunda con 10 y la tercera con seis, con al menos un hijo diagnosticado de transtorno, todos de sexo masculino. Del análisis de contenido temático surgieron las siguientes categorías: "*Retos de la maternidad atípica y COVID-19*"; "*TEA en tiempos de coronavirus: estrategias de (auto)regulación*" y "*Incertidumbres sobre el futuro*". **Conclusión:** en el actual contexto pandémico vivido, la rutina familiar de las personas autistas presentaba alteraciones con posibles perjuicios para la salud mental de todos los implicados en el cuidado. Estos resultados apuntan a la necesidad de formular estrategias que contemplen el bienestar y minimicen el impacto en el día a día de las personas.

Descriptores: Trastorno del Espectro Autista; COVID-19; Salud mental; Impacto psicosocial.

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INTRODUCTION

The world's population has been experiencing difficult times, especially in relation to the need for isolation and social distancing due to the pandemic caused by COVID-19. What has been noticed is that protection and prevention measures at a time like this have strongly influenced psychosocial issues, which can exceed people's coping capacity at different levels of severity and intensity. Health organizations around the world recommend structuring a broad care plan with the inclusion of actions at levels of integrated complementary support, ranging from broad intervention strategies with the general population, to the guarantee of specialized care for people with more severe conditions[1].

It is understood that children and adolescents with Autism Spectrum Disorder (ASD) have been considered one of the most impacted groups, due to the clinical characteristics presented by individuals on the spectrum, especially in domains related to language and social and sensory skills, which can have repercussions on the difficulty of understanding the pandemic situation and adapting to changes, especially in the context of routine[2-3]. Thus, people with ASD have become a vulnerable population that needs special attention regarding prevention and control strategies for COVID-194. Considering this, in July 2020, Federal Law No. 14,019 was enacted in Brazil, which waived the mandatory use of respiratory protection masks for people with ASD, according to a medical statement[5].

As a result of the rapid progression of contamination by COVID-19 and the exacerbated increase in the lethality of the disease in Brazil, the so-called "quarantine" caused the closure of services considered non-essential in almost the entire national territory. With a scenario of interruption of some consultations and systematic health monitoring, alternatives have been developed as responses to society regarding new ways of developing therapeutic follow-ups for children and adolescents with ASD, of which online consultations have become be a care alternative[6].

Nevertheless, families that have children or adolescents diagnosed with ASD have to deal with feelings of fear in the face of the demands of this new experience, as changes are triggered in the family due to adjustments and continuous monitoring, generating impacts on family relationships and readaptation of their members' roles[7-9]. These factors reinforce the need to develop strategies that guarantee the family well-being of these people, and aim to mitigate the consequences of social isolation[10].

Interactions with other children were significantly reduced and the possibilities of experiencing systematic experiences of building other knowledge, actions and values were restricted to the family environment for practically all families in Brazil and around the world.

The sudden change of routines for children, in general, and especially for children with ASD, has consequences on their ways of living and behaving. Therefore, multidisciplinary interventions[11-12] aim to increase the independence of individuals with ASD and become part of their routine, enabling adaptations to certain behaviors and conditions necessary for their emotional well-being, trying to bring them closer to a world of more meaningful human relationships, helping to minimize suffering in the face of isolation and social distancing.

It is noticed that in the current context experienced worldwide, the routine of families has undergone significant changes, capable of causing serious damage to the mental health of parents or caregivers of the autistic person, a fact that shows the importance of monitoring the psychological risk of these families who are in home isolation. In this direction, this work aims to verify the repercussion of social isolation for families with children and adolescents with Autistic Spectrum Disorder.

METHODS

This study was exploratory-descriptive, with a qualitative approach carried out online with mothers, fathers and/or caregivers of children and adolescents with ASD. Qualitative research works with the universe of meanings, motives, aspirations, beliefs, values and attitudes, which corresponds to a deeper space of relationships, processes and phenomena that cannot be quantified and reduced to the operationalization of variables[13].

The time frame of the research was a longitudinal, prospective follow-up, carried out from April to October 2020. In itself, data collection was divided into three stages: the first phase took place from April to June, the second phase between the months of July and August and the third phase in the month of September to October. These phases were aimed at:

- first phase: knowledge of the families' pre-pandemic socioeconomic reality, as well as the feelings and emotions that permeated the family reality at that time;
- second phase: adaptation process to the new reality and what changes were necessary in the family and therapeutic routine for the child or adolescent with ASD;
- third phase: how families organized themselves in the face of the pandemic reality, as well as the feelings and emotions that permeated family members, with their losses, bereavements and domestic and therapeutic dynamics.

Participants were invited to continue the research, and those who were interested, participated in the next phase.

Data were collected online, through a semi-structured, self-administered questionnaire and through the Google Form platform. The instrument contained questions regarding the sociodemographic data of the participants, and about the repercussions of social isolation for the main caregivers and their children and/or adolescents.

The non-probabilistic sampling criterion was adopted, and, in the selection, the Snowball technique was used, which consists of the initial participants indicating new participants, and these successively indicate others[14]. The perspective of nominations happened only until the first phase, so that the final sample considered participants from all phases.

The main caregivers were invited to collaborate with the study through social networks, such as Instagram, Facebook, WhatsApp and e-mail, and upon acceptance, the self-administered questionnaire was forwarded, along with an invitation letter, which replaced the Free and Informed Consent Form, in the sense of the manual signature of the researches. After reading and electronic consent, caregivers were directed to the research questions.

Inclusion criteria were: mothers, fathers and/or main caregivers of children or adolescents with ASD who agreed to participate in all stages of the research. Mothers, fathers and/or main caregivers of children or adolescents with other health conditions, who did not have access to the internet and the research platform, as well as those who did not respond to the questionnaire at all stages, were excluded from the study.

Thematic content analysis was used, supported by the construction of categories, for interpretation and integration of data[15], which were analyzed following the pre-analysis phases; exploration of the material; treatment and interpretation of the results obtained so that it could obtain, through the answers, the nuclei of meaning.

Participants were identified by the letter "P" followed by a number (1 onwards) to ensure confidentiality and security of anonymity. This study was approved by the Research Ethics Committee of the Universidade Federal do Triângulo Mineiro, under CAAE: 31115220.4.0000.5154.

RESULTS

In the first phase, 30 participants were considered, in the second 10, and in the third phase six. From the analysis of sociodemographic identification, it was possible to observe that all who participated in the three phases were mothers, with an average age of 40 years (minimum age of 34 and maximum of 57 years). In terms of education, two participants had incomplete Higher Education, one had completed Higher Education, two had completed Graduate studies and one had incomplete Graduate studies.

In the third phase, the participation of six mothers was considered, of which five lived in the state of Minas Gerais and one in the state of São Paulo. As for income, two mothers were employed in the public sector and two in the private sector; one mother was self-employed and one was a full time carer for her child. And two participants received the income transfer benefit "*auxílio emergencial*" (emergency aid) granted by the Brazilian Federal Government during the pandemic.

The mothers had at least one child diagnosed with ASD, all male, aged between three and 14 years. Regarding marital status, five were married and one lived in a civil partnership.

Due to the pandemic, the family dynamics were altered in many households, such as the number of people who started to live together for some period of time, due to unemployment, or the need to share income, or, even, some member belonging to the group at risk and therefore needing more care. Two families had changes in the number of people residing in their households.

The lack of support networks at this time of the pandemic, especially of professionals who assisted children/adolescents with ASD, was reported in the three phases of the study.

As for social isolation, some mothers reported that they were doing it and that the main reason for this was related to the recommendations of health authorities and to avoid contagion by the virus. But when asked how many times they went out a week, they answered that they had gone out at least one day a week, because not all of them were working at home (home-office).

From the analysis of the online research forms and the participants' reports, three thematic categories emerged: "*Challenges of atypical motherhood and COVID-19*"; "*ASD in times of coronavirus: (self) regulation strategies*" and "*Uncertainties about the future*".

Challenges of atypical motherhood and COVID-19

There were reports of physical and mental fatigue as a result of the pandemic:

Sometimes I'm tired. (P1)
Excessive obligations. (P5)

Positive points were also pointed out, such as: being able to closely monitor the development of their children and spending more time with family members:

More time with my kids. (P2)
Yes. I spend more with the family. I learned to value this coexistence [...]. (P4)
Yes, enjoying my son full time and doing household chores together. (P6)

ASD in times of coronavirus: (self) regulation strategies

As a result of isolation, mothers observed that their children showed behavioral changes that caused them suffering:

Anxiety our biggest challenge. (P1)
Anxiety, restlessness. (P2)
Behavioral issues, difficulty accepting rules. (P3)
He has difficulty accepting the change in his routine and he suffers from it and I suffer from seeing him suffer. (P4)
Irritability, disobedience and hyperactivity. (P5)

To minimize these impacts, daily activities, games and dialogue were used as coping strategies:

Talking a lot, giving attention, activities, not being too rigid in education. (P2)
I'm looking to play... ludic activities. (P3)
I talk, explain, joke around to change the focus. (P4)
I've been doing activities with him, and whenever I have the opportunity to use something from home to teach him something, I don't waste time. (P6)

Children and adolescents also created mechanisms to self-regulate, according to mothers:

He runs, uses therapy ball, a blanket and a weighted vest. (P1)
He jump and wave his hands. (P3)
He listen to music, uses therapy ball, sits on the ball and rocks or swings on the couch. (P5)
He listening to music, runs. (P6)

Uncertainties about the future

Regarding the flexibility measures, the mothers showed concerns about the increase in virus contamination, but that some activities could be resumed:

Early on, the population has been neglecting care for their own health and that of others, acting as if the pandemic did not exist. (P2)
Isolation is important but it is not possible, as many people are left without their livelihood. Adapting our daily activities to the prevention rules against the coronavirus is essential [...] *to respect preventive procedures such as using a mask, washing hands and maintaining social distance.* (P4)
I think it is necessary to resume some activities, I believe that at this moment isolation should be optional. (P5)

Other feelings emerged, such as insecurities, uncertainties and fear about expectations for the future:

Worry. (P1)
I have hope of carrying out my plans, but I am aware that nothing will be like before. (P4)
Uncertain future, insecurity. (P6)

DISCUSSION

Regarding children and adolescents with ASD, it appears that the overload and emotional readjustment suffered by the family were intense, and mothers, mainly, carried a feeling of insecurity in relation to child development during social isolation, in addition to concerns related to the risk of contagion of COVID-19, which generated greater physical and psychological tension, especially in caring for their children, bringing higher levels of family stress, in addition to the feeling of lack of a social support network[16-22].

With COVID-19 and the quarantine period, everyone's lives have been affected. In addition to the fear of illness and death, the economic consequences and the stress of social isolation, there were factors associated with the children, making the parents feel tired, sad, distressed and discouraged[23]. A study also highlighted that the suspension of face-to-face therapeutic care for children and adolescents brings relevant difficulties for both physical and emotional development, since they depend on a complex network of health service providers[22]. This point could be observed in the work presented here in the mothers' reports when asked about the future.

With children spending more time in the domestic environment, the demand for care on the part of mothers has become uninterrupted, which has doubled their working hours, a context that goes against other work[6].

Among the experiences of overload, there is the almost exclusive care for the woman (mother) with the children, with renunciation of the profession to dedicate herself exclusively to the children. In addition to the need for care in the case of children and adolescents with ASD, the period of COVID was extended by the change in routine, the fragility of family and social support[4,6,24-25].

Regarding the lack of a support network and professional support brought by mothers, an investigation is in agreement, such as a project carried out by a federal university during the pandemic, which held online conversation circles with mothers of children in severe psychological distress[6]. This is because the mothers also reported the anguish of no longer having direct access to health professionals, given the needs of their children. Furthermore, the disruption of the school routine also had an impact on family relationships, as the school is considered a source of support and a place of support[6].

This whole process of social isolation allowed mothers new perspectives on their children and the reality that both share. The most exclusive period in the quarantine allowed them to perceive many different possibilities of raising that a child has[6]. Still, spending more time with their children and family was illustrated by mothers as a positive aspect of social isolation. This distance made it possible for parents and children with ASD to come together, which generated new interpersonal development possibilities. Sometimes, crises create possibilities for deepening affective bonds[23].

The lack of assistance that families felt from the professionals who accompanied their children led them to create strategies to help their children/adolescents, as they perceived a regression in their development.

With the apparatus of "doing", the activities developed by therapists are made available to the individual, to enable: stimulation, integration (sensory and social), exploration, preparation, manipulation, organization, adequacy and orientation[12]. In other words, professional recommendations can help families devise coping strategies and minimize the impacts of social isolation.

As for the children, this reality caused suffering, as they were isolated, they became increasingly stressed when faced with breaking the old routine. This created a new demand for mothers who had to reinvent everyday life at home resorting to other leisure strategies that connected children with play. The presence of limited patterns of interests[11] and the difficulty of adapting to the symbolic world, characteristics of ASD, make games and activities monotonous. Thus, it is desired that caregivers have time to explore playful possibilities together with their children[6,23].

In an investigation with 47 Spanish families of children and adolescents with ASD, they also benefited from this extra time with their sons and daughters, and dedicated themselves to teaching new skills related to their autonomy, to house care routines and social skills and communicative interaction[10] .

Dealing with the interruption of schools, suspension of health services, therapeutic assistance and the lack of ties with other family members and friends, in addition to the fear of possible contamination, led to the appearance of inconstant behavior, anguish and fear, especially for the people who needed special care, in particular, people with ASD[22,26].

There was a lack of support from public policies to meet the needs of autistic families. In that period, families are right to feel distressed by the abrupt interruption of the intervention process, since many of the skills of children with ASD are still in the learning process and non-stimulation can lead to setbacks and delays in the acquisition of skills[26].

The challenges that people with ASD face are many and encompass a range of processes caused by stress due to the lack of understanding of the current moment, which can lead to situations of anxiety and depression[26]. The fact that the research participants also observed that their children were dysregulated, made them propose and establish other forms of care to help them during moments of anguish and emotional dysregulation.

At the height of social isolation, there were significant changes in everyone's lives, so that everyone had to adapt to the new living conditions. In the case of people with ASD, it was more complex, as most were resistant to changes, which could trigger emotional and behavioral changes[23].

A study carried out with parents and guardians of children with ASD considered the pandemic context as a period of change and restrictions, more challenging and with demands for more commitment than before, in addition to increasing difficulties in managing daily activities, in which, a out of three children had more frequent or more intense behavior problems[27].

In another study, it was demonstrated that parents perceived greater variability in the mood and irritability of their children with ASD, with increased fear, lack of motivation, and even self-harm; which could be related to the intention to express emotions or mood swings, representing a protective factor for dysfunctional behaviors[4].

The process of acquiring these children's performance skills requires direct and intensive monitoring with the family or guardians, especially with regard to routine, feelings and learning. Thus, it is imperative that children and their families carry out specific follow-ups to help them in this process.

That said, in a global pandemic scenario, such experiences tend to intensify, as the few sources of support in the care of children and adolescents have been suspended and, thus, family members and main caregivers have also been affected. Thus, care strategies that seek to support the particularities of these families are necessary[24].

When dealing with childhood and adolescence, it is everyone's duty (State, community and professionals) to guarantee protection and care for the integral health of these subjects. It is urgent to reflect on how the different contexts and actors can contribute to guaranteeing these rights, which, in the face of the pandemic, are at even greater risk of being neglected[24].

CONCLUSION

The absence of policies that can guarantee the permanence of the therapeutic routine of care for the mental health of children and adolescents with ASD and not culminate in the loss of skills, especially during the school period, seem not to have been addressed from the beginning of the pandemic until now.

The repercussions found in the study are related, above all, to the family routine of autistic people, as they presented alterations that could harm the mental health of all those involved in the care. The findings of this research suggest that everyday activities, including recreational, therapeutic and leisure activities adapted to the reality of families who were in social isolation, were important tools for coping with and solving problems and contemplate the current context of children and adolescents with ASD.

As limitations of this study, it is pointed out that it is restricted to the Southeastern region of Brazil, which does not allow generalizations regarding perceptions and coping strategies in relation to social isolation in other parts of the country. Furthermore, there were significant losses of participants during the study, as it started with 30 and ended with six; it is possible that the lack of computer knowledge and internet access had an influence.

The post-pandemic world will undergo psychosocial, behavioral, cultural, environmental and economic changes, making new research necessary to understand how and what will be the influences on child and youth development, routine and family structure and its implications for the future, notably in children and adolescents with ASD.

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