

Reflection Article/Essay

Everyday challenges and caring possibilities for children and adolescents with Autistic Spectrum Disorder (ASD) in the face of COVID-19

Desafios cotidianos e possibilidades de cuidado com crianças e adolescentes com Transtorno do Espectro Autista (TEA) frente à COVID-19

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Abstract

Introduction: In the current scenario of COVID-19 and its emergency demands, it is essential to understand the pandemic and its possible impacts, especially with regard to the most vulnerable social groups, such as children and adolescents with Autistic Spectrum Disorder (ASD). **Objectives:** This article aims to reflect on theoretical and clinical aspects of the challenges and possible implications of the current pandemic in everyday lives of children and adolescents with ASD, presenting possibilities of care based on Psychosocial Care for this population and their families. **Method:** This is a reflective essay, elaborated from the actions developed in a university project entitled “Caring strategies in Child and Adolescent Mental Health in the face of the COVID-19 pandemic”, at Federal University of São Carlos (UFSCar). **Results:** Different caring strategies regarding the implications of the pandemic in the daily lives of children and adolescents with ASD are presented and discussed, and they include the organization of routine, informational interventions, support for the families, among others. It is understood that the caring strategies permeate the individual level and the demands of the family, as well as, more broadly, the importance of the collective and the community. **Conclusion:** There is a need for further studies related to clinical practices and studies that are based on the particularities of this population during the pandemic, in order to better cope with the situation.

Keywords: Autistic Disorder. Child. Adolescent. Coronavirus Infections. Occupational Therapy.

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Resumo

Introdução: No cenário atual da COVID-19 e das conseqüentes medidas emergenciais para seu enfrentamento, é fundamental compreender sobre os impactos gerados por esta condição em grupos sociais que vivenciam condições específicas, como é o caso das crianças e adolescentes com Transtorno do Espectro Autista (TEA). **Objetivos:** Refletir a partir de aspectos teórico-práticos sobre os desafios e as possíveis implicações da atual pandemia no cotidiano de crianças e adolescentes com TEA, apresentando possibilidades de cuidado fundamentadas na Atenção Psicossocial junto a essa população e suas famílias. **Método:** Trata-se de um ensaio reflexivo, elaborado com base em ações desenvolvidas em um projeto de extensão universitária intitulado “Estratégias de cuidado em Saúde Mental Infantojuvenil frente à pandemia da COVID-19”, na Universidade Federal de São Carlos (UFSCar). **Resultados:** Diferentes estratégias de cuidado frente às implicações da pandemia no cotidiano de crianças e adolescentes com TEA são apresentadas e discutidas, sendo que estas envolveram a organização da rotina, intervenções informacionais, apoio à família, entre outras. Compreende-se que estas perpassaram o nível individual, assim como consideraram as demandas da família e, de forma mais ampliada, a importância do coletivo e da comunidade. **Conclusão:** Evidencia-se a necessidade do investimento em práticas e estudos que se pautem nas particularidades dessa população durante a pandemia, de forma a contribuir para o melhor enfrentamento da situação.

Palavras-chave: Transtorno Autístico. Criança. Adolescente. Infecções por Coronavírus. Terapia Ocupacional.

Introduction

COVID-19 is an infectious disease caused by the new Coronavirus, first identified in December 2019, in Wuhan, China. The World Health Organization (WHO) declared, on January 30th, 2020, that it was a Public Health Emergency, being decreed, on March 11th, as a pandemic (Organización Mundial de la Salud, 2020).

The best way to fight the disease has been through preventive actions, following control and protection measures, such as handwashing, wearing masks and social isolation as a way to prevent the spread of the disease (Organização Pan-Americana de Saúde, 2020).

The COVID-19 pandemic has generated a series of changes in the lives of families and society in general, which may impact on physical, mental and social aspects of health. As an example, social isolation and other recommendations, necessary for the prevention and reduction of disease transmission, end up significantly disrupting routines, which can result in tension, fear, stress, and anxiety (Fundação Oswaldo Cruz, 2020).

In this regard, it is necessary to reflect on how macro-social issues are related to the consequences caused by the disease and the way in which it affects different social groups (Farias & Leite Júnior, 2020). Minorities - indigenous people, homeless people, people with physical disabilities or mental disorders, among others - are configured as social groups that accumulate discrimination and, consequently, have less access to health

services and other social rights, being more impacted in crisis scenarios (Kupper & Heydt, 2019).

Inserted in this context are children and adolescents with Autistic Spectrum Disorder (ASD), which is a neurodevelopmental disorder, beginning in childhood, whose main characteristics are the presence of difficulties in language/communication, social interaction, and behavior (American Psychiatry Association, 2013). For this specific population, it can be difficult to understand the pandemic scenario and all the ramifications resulting from COVID-19, especially when it comes to younger children and/or those who have intellectual and sensory disabilities concomitant to their condition (Houting, 2020).

For this reason, children and adolescents with ASD can be considered more vulnerable to COVID-19, not because they are susceptible to the complications of the virus, but because of the clinical conditions that weaken their understanding of the pandemic, as well as its necessary control measures, exposing them to greater risks of contamination.

Thus, considering the particularities present in this picture, all the existing complexity and the current pandemic scenario, it is essential to reflect on the impacts of this global health crisis on the daily lives of this population, since they already naturally experience very difficult and challenging situations.

Based on a search in the current literature on the COVID-19 pandemic and possible associations with ASD, few publications were found, these being mostly institutional and informative productions that provide tips and guidance to families and professionals on how to manage everyday difficulties during the pandemic (Sociedade Brasileira de Pediatria, 2020; Narzisi, 2020; Laboratório de Terapia Ocupacional e Saúde Mental, 2020).

Only two productions from scientific journals in editorial format were found, these being international (Narzisi, 2020; Houting, 2020). In the first, the author states that, although necessary, the control and protection measures adopted by countries to contain the spread of the virus and consequent contagion of the population must be carefully managed to avoid the intensification of psychological suffering in families and behavioral difficulties in children with ASD. Accordingly, the text presents ten tips that aim to help families to deal with these children during the pandemic, such as how to explain to them about what the disease is, how to organize daily activities, how to have time for playful activities, how to use games for teaching, online therapy, among others (Narzisi, 2020).

In the editorial proposed by Houting (2020), the author, who also has ASD, reports on the process of social isolation and its implications for the lives of adults with this condition, considering that they have faced the situation in different ways, depending on personal, contextual, political and, above all, current health systems. In addition, the author points out that the current moment has mobilized the community to engage in solidarity actions and to deal with the invisibilities of the most vulnerable populations.

In Brazil, only informative materials were found, in the form of manuals and infographics that address the need for special attention to this population during the pandemic (Sociedade Brasileira de Pediatria, 2020; Laboratório de Terapia Ocupacional e Saúde Mental, 2020).

Faced with this scenario and its emergency demands, it is considered pertinent to develop studies and practices based on scientific evidence that can favor the development of strategies to fight the pandemic, especially regarding specific populations, as is the case of children and adolescents with ASD and their families.

As follows, this manuscript seeks to reflect on the challenges and implications of the COVID-19 pandemic in the daily lives of children and adolescents with ASD, and on the possibilities of care for this population and their families from the perspective of psychosocial care.

Such reflections have been elaborated based on actions that are in progress through a university extension project entitled “Care strategies in Children's Mental Health in the face of the COVID-19 pandemic”, at the Federal University of São Carlos (UFSCar). The project is divided into four work fronts, one of which is aimed at children and adolescents with ASD and their families, through which some actions have been carried out, namely:

- a) Creation of informative materials for the community: aiming to make the population aware of what ASD is and the implications of the pandemic in the lives of the families who deal with it, materials in the form of an infographic and booklets were prepared. These, in addition to addressing the importance of solidarity and support networks for these families, highlight the particularities of people with ASD, aiming at respecting and guaranteeing their rights. For the families themselves, materials were developed with the main objective of guiding them on possible strategies for coping with difficulties.
- b) Creation of a virtual communication channel of support for families: The families of children and adolescents with ASD, linked to an occupational therapy service in a city in the interior of the State of São Paulo, were invited to participate in a collective virtual communication channel. In this channel, different subjects are approached, based on different tools. For example, a folder with activity tips for children in the home context was set up; videos that discuss routine and information related to assistance services were shared.
- c) Proposition of strategies to guarantee the rights of people with ASD: through social networks, some animations or folders that addressed the rights of this population were disseminated. Also, together with other institutions in the municipality targeted by the actions, a request was filed with the Public Defender's Office regarding the flexibilization of the use of masks within this population, as well as the flexibilization of social isolation for them in a possible scenario of lockdown, in case there was an aggravation of the health situation.

To operationalize these actions, the extension project has an interprofessional team, composed of 17 members, these being teachers, undergraduate and graduate students in Occupational Therapy, Psychology, Nursing and Medicine. Additionally, actions are planned in systematic biweekly virtual meetings with this group.

The Field of Childhood Mental Health and Psychosocial care: Fundamentals for Caring for Children and Adolescents with ASD

In this section, we intend to briefly elucidate some of the main foundations that support the extension actions developed, as well as the reflections proposed in this essay. Thus, notes on the theoretical-practical framework of Psychosocial Care (Yasui, 2010; Costa-Rosa, 2013) and what has been addressed by national public policies that support the field of children's mental health will be presented (Brasil, 2015).

Costa-Rosa et al. (2003) affirm that the psychosocial attention linked to the psychiatric reform movement supports a set of theoretical-practical, political-ideological and ethical actions of an innovative character, with the intention of replacing the asylum model. According to the authors, it is not just about the transformation in mental health services or institutional organization, but rather about the way in which society is cared for and reinvented, getting psychological suffering to another place, respecting differences and understanding health as production and promotion of autonomy, freedom and defense of life.

However, when it comes to children's mental health, the transformation in care took place rather late and often tied to adults. It was only with the III National Conference on Mental Health, in 2001, that the construction of public policies and specific care strategies for this population started to be considered (Couto & Delgado, 2015).

Currently, Psychosocial Care, in Brazil, presents itself as the structuring arrangement of the Psychosocial Care Network (RAPS, in Portuguese), theoretically and methodologically supporting the work and care process that guides its functioning, as well as the organization of its devices and practices. Although the Psychosocial Care Network has been proposed considering the most diverse vulnerable groups, such as children and adolescents, its constitution is based on what was the model and philosophy of mental health care for the adult population (Fernandes et al., 2020).

For that reason, considering the particularities of childhood and adolescence, the Ministry of Health launched, in 2014, a document entitled "Psychosocial Care for children and adolescents in SUS (Unified Health System): weaving networks to guarantee care". This document points to the construction of child and adolescent mental health care based on some guidelines that highlight a series of specific aspects for this population (Brasil, 2014). It is based on this transformation that it becomes possible to detect a model of assistance to children and adolescents, as well as a dynamic functioning of the network, so that the pillars that support this transformation, such as the exercise of citizenship rights and social inclusion can actually be experienced by the assisted population (Fernandes et al., 2020).

Specifically in relation to children and adolescents with ASD, and, although public policies in the field of mental health contemplate some of their particularities, the Ministry of Health published, in 2015, the "Care Line for Attention to People with Autism Spectrum Disorders and their Families in the Psychosocial Care Network of the Unified Health System (SUS)" (Brasil, 2015), reinforcing the understanding of ASD as a mental disorder.

In this document, some fundamental principles related to assistance to this population, which correspond to the dimension of Psychosocial Care, such as the encouragement of autonomy, respect for subjectivity, integral care, the guarantee of

rights and citizenship, the inclusion of family members in the assistance process, among others, are presented (Oliveira et al., 2017).

Reaffirming the commitment to significantly expand access and quality of care directed to people with ASD and their families, it is considered essential that each point of attention at the Psychosocial Care Network is responsible for offering diverse access possibilities and different care modalities, to understand and respond to the needs of people with ASD in their life contexts (Fernandes et al., 2020). In other words, care actions and strategies must, in addition to investing in the construction of autonomy for people with ASD, support their families so that they can promote their own health, sustaining their participation in social and collective spaces.

Based on this perspective, the following are some considerations regarding care strategies referring to the implications of the pandemic in the daily lives of children and adolescents with ASD.

Care Strategies Considering the Implications of the Pandemic in the Everyday Lives of Children and Adolescents with ASD

This section does not intend to exhaust the possibilities and strategies of psychosocial care for the population with ASD and their families in considering the COVID-19 pandemic, nor to respond to all existing demands, even though the recent pandemic scenario requires professionals to create and propose actions in real time. It is understood that the impacts of this disease on both the world and the national scene are still incalculable, as it is an emerging health crisis.

Routine as a protective element

The literature in this area indicates that routine is already a point of attention commonly addressed by professionals who work with this population, as the changes that occur daily have great potential to cause suffering to people with ASD (Brasil, 2015; Machado, 2019). Furthermore, considering the emotional and task overload that families are facing, the aim is not to create new demands that could outweigh their daily life, but, rather, alleviate the possible difficulties and suffering that may arise due to this issue.

It is believed that organizing the routine of children and adolescents with ASD, in such a way as to ensure greater predictability of daily activities, is an essential care strategy to be adopted in times of pandemic. This structuring can take place through using different tools, such as pictures, images/figures, so that they understand the time to sleep and wake up, eat meals, and do other activities of daily living. It can also be related to the guarantee of moments leisure and games, as well as structured activities that require more attention and concentration, such as those related to pedagogical content. It is noteworthy, however, that it is necessary to contextualize the different realities and specificities present in the lives of each child and adolescent, as well as the existing difficulties and those that emerged from the current scenario, in order to alleviate feelings that may generate emotional disorganization (Laboratório de Terapia Ocupacional e Saúde Mental, 2020).

Thus, the active participation of the child/adolescent and their family in proposing such routines is something to be fostered by mental health professionals, to guarantee subjectivity, as proposed by Costa-Rosa (2000).

Reducing the possible damages caused by social isolation to kids with autism and their families

Social isolation measures and the need to stay at home can, at times, generate situations of intense suffering - stress, anxiety, aggressiveness, and self-injurious behaviors. Because of that, families may feel the need to make the situation more flexible to avoid further difficulties.

In this case, families can leave the house with the child/adolescent, preferably going to open spaces and at times when there are less people on the streets, so that they can walk outdoors or allow the child/adolescent to explore outside, considering all security measures and seeking to ensure the necessary protection.

Although this is not recommended for the population in general, this has been an important care strategy both to alleviate and to prevent the intensification of the suffering of people with ASD, which has been adopted in different countries, in the form of legislation, including in contexts in which the lockdown was adopted, such as in France and Spain (Notícias Uol, 2020; Confereración Autismo España, 2020).

Therefore, it is observed that, in addition to the care strategies that involve direct actions for children and adolescents with ASD and their families, it is important to reflect more broadly on the role of the government and public policies at this time, in hopes to guarantee the rights of people with ASD in the pandemic, as well as their families.

It is considered that for the effective paradigmatic transition from the asylum to the psychosocial model, there are some factors that can contribute to this transition, and that are certainly related to local historical, conjunctural and political singularities (Mondoni & Rosa, 2010). It is necessary to invest and transcend some barriers, in view of the need to transcend and expand policies and guarantees of execution, considering the complexity and uniqueness of childhood and adolescence (Fernandes et al., 2020), as is the case of children and adolescents with ASD in this very peculiar scenario.

About the use of masks

In some cases regarding children and adolescents with ASD, the use of a mask will be unviable, depending on their level of impairment, especially for those with intellectual and sensory ones. Thus, attempts to make them use it can cause intense suffering and crises and, in this case, it is important to intensify other control and protection measures (Sociedade Brasileira de Pediatria, 2020).

On July 2nd, 2020, the Federal Law Number 14.019 was enacted in Brazil, which dispenses with the mandatory use of a mask for people with ASD and other disabilities who may implicate in difficulties of using it properly (Brasil, 2020).

However, if the use of a mask is a possible option to be adopted, some strategies may contribute to making the experience less unpleasant, such as the use of more malleable fabrics and soft textures, as well as, for example, wider elastics that are attached to a prop

such as bows or bands. Other strategies can also be adopted as part of the adaptation and acceptance process, such as explaining what the disease is in a playful way and, consequently, how to prevent it; manufacturing the masks in a playful and participatory way; inserting the mask in times of playfulness, among others (Sociedade Brasileira de Pediatria, 2020).

Informational interventions

Informational Interventions are those that seek to transfer information between people, and when used strategically, they can serve as a link between health professionals and communities (Moraes, 2008). Interventions like these consider the diverse cultural, economic, and social contexts of people, as a way to facilitate the transmission of knowledge in an ethical manner that promotes citizenship, social participation, in addition to broadening the debate on diversity, subjectivity and rights.

It is understood that to advance in the perspective of psychosocial care, this type of strategy is fundamental, since it covers different instruments used in the interventions, possibilities of exchange between the subject, the care network and the community, and considers the political and socio-cultural ends resulting from produced practice, as presented by Costa-Rosa (2000).

In the current scenario, the use of interventions of this nature is paramount, especially with populations more amenable to care, as is the case of children and adolescents with ASD. As an example, in the project reported in the present study, the team prepared three materials in the form of an infographic and an animation aimed at the families of children and adolescents with ASD and the community. In these, it was possible to make the population aware of what ASD is and the implications of the pandemic in the lives of these people, to address the importance and the need to create solidarity and support networks for them and their families and to highlight the particularities of people with ASD, aiming to respect and guarantee their rights.

The materials were elaborated from the identification of their demands, being constructed with an accessible language, aiming at the greatest reach. Thus, the productions were advertised on services, social networks, radio and television.

Hence, it is the duty of the University, therapists and other professionals who work in this field and who make up the care network, to take responsibility for actions of this nature, since the care network for children and adolescents is still fragile (Fernandes et al., 2020).

It is considered that both the shared and the produced knowledge bring many potentialities and possibilities of care for a population that often does not have access to this information.

The family as a target of psychosocial care in the pandemic context

Although the strategies mentioned in the previous items directly involve the families of children and adolescents with ASD, this section seeks to emphasize the need for specific care for families, since dealing daily with the difficulties arising from ASD may generate intense suffering for those involved in caretaking. It is emphasized that, in

psychosocial care, the object of care is the family unit in all its complexity, as a fundamental integrant in the care process (Mielke et al., 2010).

This perspective finds support in the literature, which points to the burden experienced by family members of children and adolescents with ASD, due to the accumulation of tasks aimed at the care of these individuals (Minatel & Matsukura, 2014). In addition, they point out that social isolation and the feeling of loneliness are frequent, resulting from the weaknesses of social support networks (Lima & Couto, 2020). In this sense, it is essential to offer social support in the performance of tasks and decisions for the care of the family, seeking to strengthen the relationships that can produce health, considering that the family is part of the social network involved in the psychosocial care processes (Coimbra et al., 2005; Pinho et al., 2010).

In a pandemic context, such experiences tend to intensify, as the few sources of support in the care of children and adolescents have been suspended, such as therapies and school. Because of this, care strategies that seek to support the particularities of these families at the present time are necessary and urgent.

It is understood that the first step refers to the awareness of the community about the issues and particularities that permeate the universe of people with ASD, especially regarding the current demands arising from the pandemic, so that everyone can have a better understanding of this reality and its difficulties, thus, enabling respect, empathy and solidarity. Houting (2020) highlights how the world and people have changed in the face of this new reality, which is evident through the solidarity network that has been spreading in favor of people with ASD, and reinforces the importance of continuing to guarantee this for after the pandemic is over.

In addition, health professionals can provide listening and welcoming spaces for families, being an important resource to help them face the adversities of the current scenario. At this moment, spaces can be realized remotely, individually or through groups in messaging applications, videoconferences, telephone calls, etc.

Another issue to be highlighted is about the perspective and fears of families about the development of their children and the continuity of therapies. Some strategies, called Telehealth (Piropo & Amaral, 2015), can be implemented, however, it is important to emphasize that, in a scenario of greater vulnerability, access to these technologies may be limited, just as this type of care has been a challenge for professionals, users and family members. As this is a global health crisis, new challenges arise every day and, consequently, so do the need to think about measures and coping strategies, amid so many uncertainties. However, as noted, the specificities of some social groups are not always covered, as is the case of children and adolescents with ASD. It is essential to tension different instances and the community to give visibility to this population.

Final Considerations

Based on the panorama presented, the reflections presented made it possible to understand the particularities that involve children and adolescents with ASD in the face of challenging scenarios, such as the pandemic. Moreover, based on the identified demands, care strategies and actions were addressed, to cover both the care of the children and adolescents themselves, and their families. It is understood that these demands pervaded at the individual level, considering particularities, as well as the

requests of the family and, more broadly, the importance of the collective and the community.

As for the limits of this study, because it is a new and, therefore, challenging situation, some demands are still emerging and it is not possible to address all of them, such as the care strategies related to the area of Education, for example. For this reason, it is suggested that future studies address this aspect and others that will certainly continue to emerge.

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