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ORIGINAL ARTICLE

EMERGENCY SERVICES IN THE CONTEXT OF THE COVID-19 PANDEMIC: FAMILY EXPERIENCES OF CHILDREN WITH AUTISM*

HIGHLIGHTS

1. Understanding the experiences of families of children with ASD.
2. Negative impact on life regarding the Covid-19 pandemic.
3. Negative experience of emergency and urgent care services..
4. Actions of families to establish resilience processes.

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ABSTRACT

Objective: Understanding the experiences of families of children with autism spectrum disorder in the context of the Covid-19 pandemic in emergency and urgent care services. **Methods**: This is a multiple case study with a qualitative, descriptive approach. The collection of evidence took place during the year 2022, in an online manner, with 13 families of children with autism, through semi-structured interviews in a virtual environment. **Results**: The evidence resulted in two thematic categories: "Pandemic" and "Experiencing urgency and emergency". The families expressed that the pandemic had a negative impact on their lives and the use of urgent services was also experienced negatively, affecting the child with the disorder, as well as their family, on different levels and aspects. **Final considerations:** Families are capable of promoting actions that directly refer to the aspect of the resilience process that their members were able to establish during this period.

KEYWORDS: Family nursing; Autism spectrum disorder; Coronavirus infections; Urgences; Child.

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INTRODUCTION

The World Health Organization (WHO) estimates that one in every 160 children worldwide has Autism Spectrum Disorder (ASD), but its prevalence in many low- and middle-income countries is, so far, unknown[1].

ASD is defined as a behavioral syndrome with changes in cognition, language, and social interaction in children, repetitive and stereotyped behavioral patterns, exhibiting a restricted repertoire of interests and activities, and attachment to routine[2]. It also covers a wide variation in the intensity of clinical manifestations in individuals, influenced by the specific development of the person, the support they need to receive, and the presence of other comorbidities. Thus, no two individuals with ASD are alike, as it is a heterogeneous disorder[3].

Understanding the experiences of families with children with ASD is essential for the development of appropriate interventions to guide care in the different spaces of the health system for children with atypical development and their families[4]. It is necessary to approach considering the specificity of each one, being essential to offer individualized support adapted to the circumstances and particular abilities of each child with ASD[3].

Specifically in emergency and urgent care services, work processes and the environment provide different challenges for children with ASD and their families[5]. This occurs due to the unpredictable nature and waiting time of these places, which can impose a difficulty for these individuals in dealing with situational demands[6], as they are exposed to sensory overloads such as bright lights, unusual and loud sounds, different smells, and new tactile and interpersonal experiences, which can create intensified behaviors and unsafe clinical interaction for children, professionals, and family[7].

Exceptional situations, such as the one caused by the Covid-19 pandemic, present potential stressors for family dynamics[8]. In this atypical scenario that affected the world, it was necessary to restructure the routine of individuals with ASD and their families. However, from the diagnosis of autism, several changes in the family's daily activities already occur to meet the child's demands, who is sensitive to changes in routine, enhancing the impact on the family context and the organization of this group's daily life[9].

Therefore, there is a demand for reflection on the specificities and complexities that families of children with ASD experienced during this period in emergency and urgent care services. Based on these aspects, the following guiding question was defined: what was the experience of families of children with ASD in the context of the Covid-19 pandemic, in emergency and urgent care services? The objective of this study was to understand the experiences of families of children with ASD in the context of the Covid-19 pandemic, in emergency and urgent care services.

METHOD

Multiple case study, with a qualitative approach and descriptive character, following the methodological framework proposed by Yin[10]. This method is capable of understanding complex social phenomena and providing a broad view of the world through one or more cases, via empirical investigation, preserving the holistic and significant characteristics of contemporary events and aiming to describe, prove, and/or identify the contrasts and similarities present between the cases[10]. With this, it was possible to understand the subjective dimension of the experiences of families of autistic children in emergency and urgent care services, based on the need to deepen this contemporary social phenomenon.

The research was conducted in a virtual environment. The participants were family members of children with ASD who participated in Virtual Social Networks (VSNs), such as WhatsApp and Instagram groups focused on ASD, where a digital folder was made available and later shared among the members. In addition to recruiting participants through VSNs, the snowball data collection method[11] was used. The inclusion criteria were being a family member of children with ASD up to 10 years old diagnosed for at least three months and who reported attending the emergency service during the Covid-19 pandemic. The exclusion criteria included being a minor family member on the interview date and/or having communication difficulties due to a foreign language or biological issues.

Initially, 27 families filled out the Free and Informed Consent Form (TCLE) online. However, four did not meet the inclusion criteria; six families were excluded for not leaving contact information, making communication with the researchers impossible; three withdrew from participating after several reschedulings; and one family was discarded due to technical problems with the interview recording, as there was too much noise at the location, making proper transcription impossible. In the end, the sample consisted of 13 families.

Afterwards, semi-structured interviews were conducted, consisting of sociodemographic data and introductory questions (such as what it was like to experience the emergency situation for the family during the pandemic, existence of positive and negative points), via the WhatsApp® application and/or the Google Meet® platform, from January to December 2022.

All interviews were recorded in audio and/or video format, as each participant was allowed to sign the Informed Consent Form and the Image and/or Voice Sound Use Request Form. The minimum interview duration was 21 minutes, while the maximum was 83 minutes. After being carried out, they were transcribed into the Microsoft Word® program.

The family was considered as the unit of analysis for this study, and the analytical strategy "treating your data from scratch" was used, an inductive strategy that allows the researcher to extract information from the data instead of starting from theoretical propositions[10].

Several readings of the collected data were made to approximate the research material, and subsequently, all interviews were systematized into matrices to facilitate the identification of initial categories. The participants in this study were identified by the letter F, followed by an Arabic numeral. Therefore, a matrix containing the empirical descriptions of the cases was developed, using the webQDA® program to assist in organizing the data analysis.

This research is part of the thematic project "Resiliência de Famílias de Crianças com Necessidades Especiais no Contexto da Pandemia de Covid-19", developed and coordinated by researchers from different universities in four states of Brazil. Approved by the Ethics Committee in Research of the Universidade Federal do Paraná, with opinion No. 6,656,186.

RESULTS

Of the 13 families that participated in the study, all were represented by the maternal figure. The families were residents of two regions of Brazil – South and Southeast – and the age of the mothers ranged from 27 to 46 years, with approximately half of them being single and/or divorced, and the majority having completed higher education. Regarding family income, the average was four minimum wages, based on the national minimum wage of R$ 1,212.00 for the year 2022.

Most of the children were male (71.4%), with the diagnosis of ASD made around the age of three. However, when considering the diagnosis in girls, the average age of diagnosis rose to four years. Regarding health monitoring and therapies performed, the one that stood out the most was Applied Behavioral Analysis (ABA) therapy.

About the reasons why families needed urgent and emergency care for children during the pandemic, symptoms of odynophagia, flu-like and respiratory symptoms stood out. It is noteworthy that four children (26.7%) tested positive for Covid-19 during the period.

From the data analysis, 250 descriptors were identified, divided into the categories "Pandemic" (82 descriptors) and "Experience of urgency and emergency" (168 descriptors).

The first category showed that families had convergent opinions regarding the pandemic, with the perception of a negative impact on their lives prevailing. The feeling of fear could be perceived in different ways, such as losing someone, the sequelae of COVID-19 because it was something unknown until then, or the illness of the child itself.

The consequences of this pandemic were pointed out by families as harmful and affected both children with ASD and other members. There have been reports of various changes, mainly behavioral, in children with ASD, but also changes that have influenced the mental health of family members. Another negative impact of the pandemic reported by families was the disruption of routine related to the suspension of in-person classes and its consequences for children with ASD, as well as the need to readapt daily habits.

Regarding the protective measures indicated for the prevention and control of the spread of COVID-19, this research observed that children older than five years had good adaptation, especially in raising awareness about the use of masks.

Overlapping the pandemic context and the need to use emergency services, two families received the diagnosis of ASD for their child, which was unexpected.

Chart 1 was created to exemplify the empirical data of the category "Pandemic".

Chart 1 – Empirical data: Pandemic. Curitiba, PR, Brazil, 2023

Category	Family	Data
Pandemic	F.2	<i>[...] what I feared most in this pandemic was the (child) catching COVID, oh, how I was so afraid.<i> *My greatest fear, my greatest care, my greatest everything was the* [child]*, and my greatest fear became a reality […].*
	F.4	*With the break in routine during the pandemic, it was striking, especially the issue of self-aggressiveness... Aggressiveness increased, she tried to self-mutilate, she hit herself a lot [...].*
	F.13	<i>The difference that school makes in life is absurd; the performance here is quite compromised, being closed all the time, how much difference socialization makes, going out, having interaction with other people.<i>
	F.9	<i>[...] he is not that child that we can say 'oh no son, this will pass', he knew everything, knew that he had to sanitize his hands, knew the seriousness, about the people who were dying [...].<i>

Source: The authors (2023).

Regarding the second category, families reinforced experiencing bad situations in establishments that provide urgent and emergency care, regardless of whether they were private or public, hospital emergency rooms or urgent care centers. This negative experience was not only related to the child's own experience but also to that of their family members who participated in this moment of acute health condition. To represent the empirical data of this category, Chart 2 was created.

Chart 2 – Empirical data: Experience of urgency and emergency. Curitiba, PR, Brazil, 2023

Experience of urgency and emergency	F.9	*[…] he was walking back and forth extremely nervous, there was a child crying with an earache, and he with both hands on his ears and walking back and forth […].*
	F.12	<i>When he was admitted to the hospital, he was salivating excessively, he wanted us to put our hands in his mouth, and I only calmed down inside, it was a horror story for me because I thought I was going to lose him.<i>
	F.10	*[…] for them there is no such thing as waiting a little longer, he is very impatient, he would hit his head on the floor, throw himself on the floor and hurt himself a lot […].*
	F.11	*[…] I don't like taking him to hospitals, I prefer him to be hyper like this at home.*
	F.13	*[…] it is practically impossible to give medicine, I sit with the doctor and say that the best is to give injectable medicine, I already ask for it right away, because the oral route is almost impossible.*
	F.6	*I always have a plan B, I always carry lollipops in my bag. Before entering the office, I hand one to the doctor and say 'right Doctor, if he lets you examine him, you'll give a lollipop to the* [child]*'.* <i>There is this "exchange" relationship with the lollipop that works very well every time<i>.

Source: The authors (2023).

In these health environments, most families reported the behavioral changes that the child exhibited, such as crying, screaming, and self-aggression. Due to previous experiences, they avoided taking the children to these places for care. Furthermore, during the procedures performed, families reported that the children reacted with agitation and behavioral changes.

On the other hand, a strengthening factor pointed out by families was always having a plan and/or mechanism to facilitate care and make it more harmonious and acceptable for the child, such as an object that the child likes or even the presence of more than one family member during care. Furthermore, a preference for intramuscular medication was observed due to previous experiences with oral and/or intravenous administration.

During the interviews, the issue of whether or not to disclose the diagnosis of ASD also arose, which is analyzed according to the child's behavior at the time, that is, families considered revealing the diagnosis when the child showed some change during the consultation, otherwise they preferred not to disclose it, due to discomfort, especially with prioritizing the child, causing reactions and judgment from other people present at the location.

DISCUSSION

As in other studies[12-13], this research only included the participation of mothers as the primary caregivers, which highlights the aspect of maternal overload. The care provided by mothers can be perceived as suffering of exclusive dedication to this child, as well as to other children, husband, and household activities, generating physical, social, and emotional overload[14]. This scenario reflects women's social place in current culture and society as the central figure responsible for the care of children and family[14].

The fact that most children are male also resembled the literature found that portrays the characteristics or epidemiological profile of people with autism, with a predominance of males[15-16], as well as the detection and diagnostic confirmation around the age of 3, with, on average, one-third to half of these children being diagnosed only at school age[17-18]. From this perspective, the data also resembled the research, in which the average age of diagnosis was 3 years.

Regarding health follow-ups, this study highlighted ABA therapy, a behavioral intervention method in the treatment of autism symptoms that is among the most widely adopted approaches worldwide to promote the quality of life of people with ASD[19].

Regarding the reasons that led to visits to urgent and emergency services, flu and/or respiratory symptoms and sore throat stood out. Other studies conducted in pediatric emergency care also indicated that the highest demand was related to respiratory tract infections, cough, and fever[20-21]. Still, it is necessary to emphasize that the pandemic significantly contributed to the increase in anxiety symptoms, such as fear itself, distress, and stress, among families who had members with ASD.

The opinions on the pandemic context converged in its negative impact on the daily lives of these families, indicating a situation of tension, suffering, worry, and anguish, which reflected not only in the routine activities of life but also in the emotional and behavior of children with ASD and their families[22-23].

In some cases, the pandemic's negative consequences also motivated emergency service visits, such as sensory crises and cognitive-behavioral alteration. Behavioral changes during the pandemic isolation period were mainly related to aggression, self-harm, anxiety, and stress[22-23].

Individuals with ASD are more likely to visit emergency services, both for clinical and mental health issues. Still, this environment is extremely challenging for this population, potentially resulting in sensory, social, communication, and behavioral changes[24], culminating in a negative experience for the child and their families.

Emergency and urgent care services have excessive auditory and visual stimuli, crowded environments, and long waits[25]. Therefore, in addition to being challenging to take a child with ASD to these environments, the pandemic contributed to the hesitation of family members in going to these places as they weighed the risks and benefits.

With the lack of a welcoming environment to better accommodate children with ASD, there are often improvisations at the discretion of the employees[26], that is, the employees try to adapt the structure and/or work process to the care of the child with ASD.

Several specific procedures during health care are identified as challenging, including the physical examination of the ears and throat, blood pressure measurement, blood collection, injections, and changes in environments[27].

Children with ASD generally tend not to cooperate with procedures, especially those considered invasive. In this way, it is necessary for health professionals and services to be sensitive to the needs of the family and to adapt care flexibly[3-4], such as, for example, the preference for intramuscular medication, due to the difficulties of oral administration at home, as pointed out by the families.

The family can use some resources, such as a favorite toy, to also help keep the child calmer and more distracted. However, there is a minority of parents of children with ASD who seek care in prepared emergency departments, possibly due to the very nature of the visit, often immediate and not having time to organize[27]. Since the family is the one who knows the child best and knows which strategies can be used to help, it is essential to listen to them to provide care that considers the child's individual needs. Recognizing and interpreting the subjectivity of the child with ASD and their family requires sensitivity from professionals and results in more effective care.

Regarding education, social isolation provided the transition from face-to-face to remote teaching, which impacted diverse audiences. Children with ASD and their families faced even greater challenges[3-4,28]. Families noticed a decline in the child's performance due to the lack of socialization, difficulty adapting the child with ASD to remote learning and the new routine, and difficulty understanding the COVID-19 pandemic and accepting individual protection measures. This highlighted the low cooperation in wearing masks, especially due to issues such as sensory hypersensitivity [29-30].

In addition to experiencing care in emergency services during the pandemic, some families received an ASD diagnosis in this context. It is understood that the diagnosis of a chronic condition is permeated by ambiguous sensations and feelings. Upon receiving the diagnosis of a child with ASD, families demonstrated that it was an unexpected event, which had repercussions in the family context and provoked a succession of feelings and adaptations. The pandemic intensified the feelings the family members experienced on this occasion[14].

Regarding the moment of the ASD diagnosis, the literature states that families initially feel comforted by understanding the perceived differences in their child's behavior; however, they then find themselves in an unfamiliar place, filled with anxieties and reinterpretations. This creates in families the need to create another chapter for their life stories, in a new world, with varied experiences and experiences[9,14].

In addition to the different adversities mentioned by the families regarding the diagnosis, there is a dilemma about whether or not to disclose it during the child's care in emergency and urgent services. Often, family members are concerned about the negative labeling of the child and the stigmas that still exist in society. Some families reported not mentioning the ASD diagnosis while the child does not show behavioral changes; others perceive that, when they tell, other family members do not understand the condition of the priority[6,26].

Finally, these families face the limitations of autistic children, and this generates fear and suffering in the face of the unknown, revealing a difficult experience in the face of the dependency situations that these children may present[9,14].

It is recognized as a limitation of this study that the participants did not represent all profiles of families of children with ASD, as well as few studies were found on the studied theme.

FINAL CONSIDERATIONS

According to the context presented by the participating families, a negative repercussion of the experience in emergency and urgent care services with their children with ASD during the pandemic was observed, with consequences that affected both the child and their family members. Emotional issues were highlighted as weakening when seeking care in these places, given previous experiences. Despite the difficulties encountered, the families were able to promote actions that favored assertive care, fully embraced by the child during the service. Therefore, it emphasizes the need to recognize each child with ASD and direct comprehensive care that meets the specificities of this group and their families.

Based on the findings of this study, it is observed that there is a need to improve the reception of families of children with ASD in these environments, as well as to promote the knowledge of health teams working in the ASD area so that they can develop better interventions with this population. It is suggested to conduct new research that can cover more families of children with ASD accompanied in emergency services in different contexts, especially atypical scenarios, such as the pandemic, in different social realities, to provide quality care with professionals trained to serve this population.

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Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - **Estevão AR, Mazza V de A, Ruthes VBTNM**. Drafting the work or revising it critically for important intellectual content - **Estevão AR, Mazza V de A, Ruthes VBTNM, Roberto FL, Guisso ACB, Moreno MEB.** Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - **Estevão AR, Mazza V de A.** All authors approved the final version of the text.

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