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THE EFFECTS OF THE PANDEMIC ON CHILDREN WITH ASD (AUTISM SPECTRUM DISORDER) AND OTHER PERVASIVE DEVELOPMENTAL DISORDERS AND THEIR FAMILIES

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ABSTRACT — AIMS: This paper investigates the effects of the pandemic on children with ASD and other pervasive developmental disorders and their families. There is a significant number of studies in the literature on the effects of the pandemic on the population, but this concept has been less studied among parents of children with autism spectrum disorder.
Thus, this paper aims to determine whether there are significant effects of the pandemic on children with ASD and other pervasive developmental disorders and their families.
METHODS: A group of participants consisting of parents of children with autism was used to conduct this research.
RESULTS: The results of the research indicate that there are significant differences in the lifestyle of parents and children diagnosed with autism spectrum, before and during the COVID-19 pandemic.

KEYWORDS — autism, family, child, autism spectrum disorder (ASD), pandemic.

INTRODUCTION

We chose to study this topic, because autism spectrum disorder is a condition that is showing an increasing incidence in the last decades.

The child with special needs has an impact on the family as well. Families play an important role in the child's recovery process, and the way family members react and the way they relate to the child and his needs, which can directly impact the child's recovery (Damian et al., 2017; Haraz, 2019; Teslenko, 2020; Valache, 2020).

Parents with children with autism experience a unique stress that is not found in any other parent with a child with other disabilities (Deater-Deckard et al.,1996).

This uniqueness caused by the fact that the parents may notice that as the child grows, loses from the acquisitions, the child seems physically healthy, but has many behavioral deficiencies. Parents experience the inability to control the child's behavior. The major source of stress for parents is related to the fact that the society shows a lack in understanding of the child's condition (Burlea et al., 2010; Woodgate et al., 2008).

In general, parents are the first to feel and realize that something is wrong with their child. Unfortunately, due to the complexity of the symptoms, but also out of ignorance, some parents wait for the child to grow up, which is a big minus in the little one's recovery (Chîlnicean, 2011).

THEORETICAL FRAMEWORK

Resilient family

With the emergence of the first theories in the literature that refer to the term family and its functioning socially, the typical family was defined as an exchange of traits, specifically, between two people of the opposite sex, resulting in the traditional family with roles and specific statuses (Parsons & Bales, 1955, cited in Finley & Schwartz, 2006). Over the past two decades, much research has shown that family processes are based on individual health and emotional involvement (Beavers & Hampson, 1990).

The parental status of a child with disabilities is built around a specific dynamic. Children are a source of joy, but also a source of unhappiness. The history and evolution of the child with disabilities begins at the moment of doubt and uncertainty at first sight of the mother of the child. At first, she examines the bodily, physical integrity of the newborn, then focuses on gender. This first look at the newborn, in the case of a child with disabilities, is loaded with doubt, which gradually becomes a certainty. The announcement of the existence of a deficiency of the newborn, the first stage of a long and difficult evolutionary process for both the child and the family, has a strong impact. In such cases, each family has its own path, its own way of reacting, depending on the personality of the members, the professional and economic situation, the geographical area in which they live, the support from the extended family, the possibilities of access to community life, etc. However, the difficulties that the family has to face are similar. (Gavriliță,2020).

In the case of families of children with disabilities, stress and involvement are stronger than in the case of families with typical children. The feeling of stress is fueled by the fact that parents face a multitude of inappropriate behaviors experienced by the child. Once the therapeutic plan is implemented, the whole family must adapt its behavior, according to the instructions given by the little one's therapist. (Gavriliță, 2020).

In practice in the office, I realized that there are families who, once they found out the diagnosis of the little one, had to change their whole life. One of the families that caught my attention, presents a little girl with a diagnosis of Autism Spectrum Disorder, but also sensory desynchronization. Due to this seasonal desynchronization, the little girl needed continuous movement, which determined the family to spend more than 20 hours a day, in the car, while walking.

Autism

Autism, until 4-5 years ago, was considered deaf. If in Down Syndrome, from a physical point of view can easily recognize the child's disease, in the case of autism, at the opposite pole, the child has a normal physical appearance. His behavior, on all levels is what betrays the disease (Chîlnicean, 2011).

Children's behaviors persist or intensify, and the faster they intervene, the more these developmental disorders can be corrected, even cured, avoiding their amplification over time. It is very important to know that for the child with autism, every second, every hour, is extremely important for the whole recovery process (Chîlnicean, 2011).

Integrated into Pervasive Developmental Disorders, along with other disorders such as: Asperger's Disorder, Disintegrative Childhood Disorder, Rett Disorder, Global Developmental Disorder — including atypical autism, as established by the American Psychiatric Association in DSM 4, Autism Disorder or a neuro-biological developmental disorder that affects the functioning of the brain, more specifically affects the normal development of the brain, which is responsible for communication, social interaction and cognitive functioning (Chîlnicean, 2011).

Specific therapies

It goes without saying that a child with a cognitive disability needs an education, with the help of specific therapies. applied behavioral analysis, ABA therapy has developed, coming to the aid of more and more families. Intensely applied, with seriousness and consistency, ABA therapy begins to bear fruit after 2-3 years. ABA can help even to full recovery, depending on how quickly the therapy started, the child's resources and his diagnosis. ABA is considered a science of human behavior. The ABA method targets the learning of certain skills and their generalization in the natural environment (Chîlnicean, 2011).

It is very important to know that every child is different, and the results are different from child to child.

METHODS

Objective

This paper aims to discover the effect of the pandemic on children with ASD and their families.

We chose this goal because I believe that Autism Spectrum Disorder is gaining momentum in today's society, and the role of the family in the context of the COVID-19 pandemic is very important, and the mission of parents is hampered by the epidemiological context we all go through.

Hypothesis

There are significant differences in the lifestyle of parents and children diagnosed with autism spectrum, before and during the COVID-19 pandemic (Luca et al., 2020).

Description of the sample

This presentation was made on a group of parents whose children were diagnosed with Autism Spectrum Disorder.

The parents belonged to an autism intervention association in Bucharest.

Research design

The research design is transversal.

This type of design was chosen due to its usefulness, but also due to the fact that the research hypothesis does not require a longitudinal design and does not present elements that require the use of an experimental design.

Data collection procedure

The data needed to make this presentation were collected from the parents of children with Autism Spectrum Disorder.

During the training, the respondents were assured that they will benefit from the absolute confidentiality of personal data according to the deontological norms approved by the Romanian College of Psychologists and according to the personal data protection law, stating that the data collected and the results obtained will be used only for research purposes.

RESULTS

The aim of the research is to find out if there are significant differences between the lifestyle of the parents of children with ASD, before and during the COVID-19 pandemic (Baroiu et al., 2021).

The results show that there are significant differences in lifestyle. The child with special needs is a real challenge for the whole family. The current epidemiological context has come as an additional challenge for the parents of these children (Grigoras & Ciubara, 2021).

There is a big difference in adapting families to this situation. Not all families are deeply affected. The variability is explained by the severity of the child's diagnosis. The main fear presented by the parents was the one related to the closure of the centers where their little ones did therapy. Following these events, the parents had to take on the role of therapist.

Another major change and a reason mattered. The concern was caused by the loss of a job of one of the parents, which meant the reduction of therapy hours for the little one.

The parents say that another provocative thing was to desensitize the child, in the direction of wearing a protective mask. Some parents say that a simple leave to the store has turned into a whole process of preparation for the little one.

In conclusion, parents realized the importance of being involved in the autism community, even during the pandemic, and that they cannot do everything on their own. Parents say that they have learned more about their children's specific needs and abilities.

DISCUSSION

The aim of the research is to test whether there are significant effects of the pandemic on children with ASD and other pervasive developmental disorders and their families.

The pandemic has certainly left its mark on all people, especially children with ASD and their families. The parents claim that at the beginning of the pandemic, they experienced feelings of fear. This fear was fueled by the whole context, but especially by the fact that most therapy centers, where their little ones carried out therapeutic programs, suspended activity. At that time, parents asked themselves questions such as: the child?" "If I do not know how to manage certain behaviors that may occur?".

Parents had to adapt to a new way for their little ones to continue therapy, this being telemedicine, online therapy.

The parents looked for solutions on social media. They joined various groups, where there were other parents in the same situation, but also specialists in the field of psychology. One of the goals of those groups was to make family members aware that they can improve their verbal and nonverbal communication skills. This helps them gain new ways to communicate and interact physically with the child with autism, as well as with other members of the family.

Parents have realized the importance of being involved in the autism community, even during the pandemic, and that they cannot do everything on their own. Parents say they have learned more about their children's specific needs and abilities and that they have communicated with other parents to learn from their experience to become better parents for their own child.

Parents say that they used social networks to get in touch with other parents in the same situation and to find solutions for the different new situations they live.

In social networking groups, parents have the opportunity to ask questions about the difficulties they face in their relationship with their children. The fact that they can learn how to manage certain behaviors, makes them no longer feel powerless and much more in control of the situation.

The parents say that until they participated in these groups, they did not have the support of the others. Most of the time, relatives or friends put more pressure on their shoulders. They saw the situation as sad, frustrating, very tiring, but because they were talking about their own children, they wanted to do everything they could. After participating in meetings on Zoom, parents found ways to communicate them to their extended family, or close friends the experience they are going through.

The effects of the COVID-19 pandemic can be seen everywhere in the lives of children with ASD and their families. The parents say that the first problem they faced was related to the difficulty in convincing the children to wear the face masks. Many children refuse to wear a mask, which develops a feeling of helplessness, frustration and confusion in their parents.

Another important thing acquired during the pandemic is the acceptance of feelings. Parents have learned to talk about how they feel. They have learned that it is normal to have contradictory feelings and sometimes be angry.

In conclusion, there are significant effects of the pandemic on children with ASD and other pervasive developmental disorders and their families. Most parents say that social media had a strong impact during the pandemic and that they felt closer to other parents through social networks. Another very important role in the whole process was played by the online workshops. Through them, the parents maintained contact with the specialists.

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