The Family Impact of the Diagnosis of Autistic Spectrum Disorder

O Impacto Familiar Frente ao Diagnóstico de Transtorno do Espectro Autista

El Impacto Familiar del Diagnóstico del Trastorno del Espectro Autista

RESUMO

Objetivo: identificar o impacto familiar frente ao diagnóstico de transtorno do espectro autista. **Métodos:** estudo descritivo exploratório qualitativo, realizado através de entrevistas semiestruturadas com uma amostra de 10 mães de crianças com diagnóstico de Autismo acompanhados em um projeto que atende crianças com necessidades especiais na região metropolitana de São Paulo. As entrevistas foram analisadas através da Análise de Conteúdo de Bardin. **Resultados:** foram elencadas quatro categorias centrais: Tendo a desconfiança prévia do diagnóstico; Sendo difícil aceitar o diagnóstico; Buscando o conhecimento para entender melhor o diagnóstico e Mudando a vida social familiar. **Conclusão:** o impacto familiar após o diagnóstico traz mudanças permanentes na família sendo necessária uma reestruturação para dar suporte a sua criança e se adaptar à nova realidade.

DESCRITORES: Transtorno do espectro autista; Família; Criança; Enfermagem Pediátrica.

ABSTRACT

Objective: to identify the family impact in the face of the diagnosis of autism spectrum disorder. **Method:** descriptive exploratory qualitative study, carried out through semi-structured interviews with a sample of 10 mothers of school-age children diagnosed with Autism, accompanied in a project that serves children with special needs in the metropolitan region of São Paulo. The interviews were analyzed through Bardin's Content Analysis. **Results:** four central categories were listed: Having the previous distrust of the diagnosis; It is difficult to accept the diagnosis; Seeking knowledge to better understand the diagnosis and Changing family social life. **Conclusion:** the family impact after the diagnosis brings permanent changes in the family, being necessary a restructuring to support the child and adapt to the new reality.

DESCRIPTORS: Autistic Spectrum Disorder; Family; Child; Pediatric nursing.

RESUMEN

Objetivo: identificar el impacto familiar del diagnóstico de trastorno del espectro autista. **Métodos:** estudio descriptivo exploratorio cualitativo, realizado a través de entrevistas semiestructuradas con una muestra de 10 madres de niños diagnosticados con Autismo seguidos en un proyecto que atiende a niños con necesidades especiales en la región metropolitana de São Paulo. Las entrevistas fueron analizadas mediante el Análisis de Contenido de Bardin. **Resultados:** se enumeraron cuatro categorías centrales: tener desconfianza previa en el diagnóstico; Es difícil aceptar el diagnóstico; Buscando conocimientos para comprender mejor el diagnóstico y cambiar la vida social familiar. **Conclusión:** el impacto en la familia después del diagnóstico trae cambios permanentes en la familia, requiriendo reestructuración para apoyar al niño y adaptarse a la nueva realidad.

DESCRIPTORES: Trastorno del espectro autista; Familia; Niño; Enfermería Pediátrica.

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Carolliny Rossi de Faria Ichikawa
Nurse. Doctorate in Sciences. Professor at the FMABC University Center
ORCID: https://orcid.org/0000-0003-3002-9448

Danila Leal Pinho
Nurse. Sírio-Libanês Hospital
ORCID: https://orcid.org/0000-0002-8051-7610

Simone Garcia Lopes
Nurse. Doctorate in Sciences. Professor at the FMABC University Center
ORCID: https://orcid.org/0000-0001-6091-3133

Isabel Cristine Fernandes
Nurse. Master's in Sciences. Professor at the FMABC University Center
ORCID: https://orcid.org/0009-0003-0880-7765

Natália Cristina Liubartas
Master's in Sciences. FMABC University Center, Lauro Gomes Street 2000, Sacadura Cabral Neighborhood.
ORCID: https://orcid.org/0009-0000-9425-7832

Sabrina Dayane Mazote
Nurse. FMABC University Center, Sírio-Libanês Hospital
ORCID: https://orcid.org/0009-0003-3602-6747

Patrícia Santos Matielo
Nurse. FMABC University Center, Hospital das Clínicas, Faculty of Medicine, University of São Paulo
ORCID: https://orcid.org/0009-0001-7442-2236

Débora Tavares do Nascimento
Nurse. FMABC University Center
ORCID: https://orcid.org/0009-0000-5376-976

INTRODUCTION

Over the past 50 years, Autism Spectrum Disorder (ASD) has evolved from a rare, narrowly defined childhood-onset disorder to a well-publicized, advocated, and researched lifelong condition recognized as both quite common and very heterogeneous. [1] This scenario can be portrayed by the high prevalence of the condition, which according to the latest survey by the United States Centers for Disease Control and Prevention (CDC) in 2020, presents an estimate of 1 case of ASD in every 36 children aged 8 years old, with boys being four times more affected by this condition. [2] The CDC thus points to the continued increase in children identified with ASD, particularly among children and girls of color, highlighting the need for improved infrastructure to provide equitable diagnosis, treatment, and support services for all children with the condition. [2]

ASD is a neurodevelopmental disorder characterized by deficits in communication and social interaction, in addition to the presence of restrictive and repetitive patterns of behavior and interests [3,4], bringing limitations in play, social interaction, verbal and non-verbal communication, stereotypical patterns and sensory sensitivity. [5] Children with ASD may present developmental problems between 12 and 24 months, and the initial signs of the disorder can be noticed in the first year of life. [4] The average age of ASD diagnosis has been around 52 months of age, when clinical signs are more evident and attract the caregiver's attention [6], that is, in most cases, parents are the first to notice their children's developmental difficulties, which are generally related to deficits in socialization skills, behavioral issues and delay in verbal language, with the absence or delay in speech being the main symptom that leads parents to seek professional help in search of a diagnosis. [7]

The diagnosis is based on clinical observations through the identification of behavioral signs, and it is worth highlighting that early diagnosis has a great impact on the potential for intervention in the early stages of child development, favoring the stimulation of cognitive skills, such as verbal language and communication; sociocognitive skills, such as shared attention; and behavioral skills, such as autonomy and social skills, contributing to the reduction of the impact of symptoms on the individual's daily life. [4-5, 8]

The search for family members until the diagnosis is finalized is often long and permeated by concerns, doubts and difficulties, and therefore, in certain situations, caregivers can react positively to the diagnosis, since it establishes a sense of control over the situation and allows the beginning of treatment with targeted interventions. [7-8] However, it is worth highlighting that, as it is a disorder whose etiology is not completely defined, as there are a variety of possible interventions and there is no "cure", the diagnosis of ASD can become especially distressing and generate uncertainty for many family groups. [10]

In this case, when receiving a diagnosis of ASD, it is common for many families to have doubts and face periods of emotional overload and adaptation, since receiving the diagnosis may cause parents to break from their expectations of an ideal child to contact with their real child, as well as uncertainty about their development and the repercussions on the family. This is because the typical symptoms and difficulties arising from ASD have been identified as potential stressors in the family context, since they can affect the way parents will raise their children, as well as the coparenting relationship, being influenced by variables such as the severity of the characteristics, the personality of the family members and the availability of community and social resources. [10-11]

Furthermore, in an attempt to alleviate the feelings caused by receiving the diagnosis, many families seek support and explanations regarding the care demands that must be developed, as it is essential to learn how to care for a child with ASD, understand their particularities and seek specialized care. As a consequence, families begin to require more information, seeking

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professionals from different areas and other sources of access to information.[10,12] In this context, the importance of establishing a partnership between parents and professionals is widely recognized, making them facilitators of the process of family engagement in the care of children with ASD and providing the necessary support to neuroatypical individuals, which is one of the key elements of family-centered care. Furthermore, it is important to seek out centers where family members can exchange knowledge with people who have similar experiences, aiming to contribute to the formation of identity and belonging.[10,12]

Therefore, it is clear that the diagnosis of ASD is a potential generator of changes in family dynamics, which requires an adaptation process that demands time and continuous dedication from all family members. This impact becomes even greater in cases of families with more children and other members living in the same residence, since the learning and dedication of caregivers in managing a child with ASD reveals other pending issues, such as the deficit in caring for other children, the spouse and their own leisure time, evidencing a stress that is always present in the family's daily life.[1,9,13] Therefore, it is essential to have the support of specialized professionals and the presence of close family and friends throughout this journey, especially during transitional moments, such as diagnosis, starting and leaving school, and changes in family dynamics. This is because families that establish a solid foundation in the psychosocial context tend to be more effective in their planning and adaptation, being able to maintain the balance necessary for quality of life in all aspects, in addition to being better prepared to find solutions in the face of crisis situations or moments of stress.[1,9,13]

Thus, the numerous particularities of ASD are indisputable, from its typical symptoms to its repercussions on the psychosocial context, which is permeated by family adaptations that are necessary in view of the special care for the child from the moment of diagnosis. However, there is a scarcity of studies on the subject in our environment, and therefore, seeking to understand the behavioral and social changes in the family of an autistic person, we ask what is the family impact of the diagnosis of autism spectrum disorder?

METHODS

Descriptive-exploratory research with a qualitative approach. For this purpose, a semi-structured interview was conducted. The analysis of the collected data raises in-depth and explanatory information about the content presented, identifying the family impact of the diagnosis of autism spectrum disorder.

The study was conducted in the metropolitan region of São Paulo with family members of children with ASD participating in a project by a non-governmental organization (NGO). The organization was founded in 2014 and serves children with special needs by performing specific and adapted physical exercises, aimed at physical motor and cognitive development. It promotes lectures and events for parents and family members of children and young people with disabilities with the objective of providing guidance and awareness.

Ten mothers of children with ASD of preschool and school age (3 to 10 years old) participated in the research, according to the ECA[14], who had been diagnosed for at least 1 year and who participated in the activities of the NGO. The inclusion criteria were: Being a mother of a child with ASD and living in the same residence as the child. Mothers with cognitive deficits or any difficulty in communication were excluded.

Data collection began after the project was approved by the Research Ethics Committee (CEP), under approval number: 72217817.80000.5512. The participants signed the Free and Informed Consent Form, in two copies, one was given to the family member and the other remained with the researcher.

The interviews were conducted at the NGO's premises in January and February 2020 and lasted approximately 40 minutes. They were recorded in full and later transcribed. The technique used was the semi-structured interview, guided by the questions: What was it like for you and your family to receive the diagnosis of autism spectrum disorder? What were the main changes in your family's routine after the diagnosis? What difficulties do you and your family face with the ASD diagnosis?

Bardin's content analysis was used to analyze the data, which aims to find the cores of meaning present in the interviews whose presence or frequency have meaning and correspond to the objective of the study.[15] The analysis is divided into three stages: Pre-analysis; Exploration of the material; and Treatment of results and interpretation. Treatment of results and interpretation consists of organizing the raw data in order to form themes, which can be defined as cores of meaning that emerge naturally from the narratives analyzed.[15] In preparing this manuscript, the criteria for reporting qualitative studies, present in the COREQ checklist - Consolidated criteria for reporting qualitative research, were taken into account.[16]

RESULTS

By raising the main points of agreement among the interviewed family members, four thematic categories were reached: Prior distrust of the diagnosis; Difficulty in accepting the diagnosis; The search for knowledge to better understand the diagnosis and the change in family social life.

Having prior suspicion of the diagnosis

The perception of prior suspicion varies according to age, so as the child develops it is possible to identify delays, bringing to light the suspicion that something is wrong. The parents' perception of the first signs of development presented by the child is related to the delay in communication and language, together with social interaction, around two years of age. Thus, when asked about what it was like to receive the diagnosis, some families report prior suspicion.

"...at one and a half years old he still couldn't talk, he couldn't look properly,

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when you called him he would take a long time to look." (P1)
"...We already suspected that there was something wrong, it took him a while to talk to walk [...] we started to connect some things and so on." (P2)
"He was born healthy and as he grew I noticed that he didn't look at me and didn't talk and so I thought that maybe it was a hearing problem [...] Talking to my son's new pediatrician about some of his characteristics, she referred me to a neurologist. I made an appointment and spent approximately 2 hours talking to her and she observed and examined him, and at the end of the appointment she said that he had characteristics of the autistic spectrum." (P10)

Parents also observed and reported concern because their children were not performing activities and playing as expected for their age compared to other children in the same age group.

"He didn't wave goodbye with his little hands, he didn't send kisses... those things that children usually do." (P7)
"As we had already noticed a certain difference and difficulty our son presented in relation to other children." (P8)

Parents are concerned about the issue of delayed language combined with socialization and behavioral deficits that appear around two years of age, at the same time that they report regression or interruption in development in several areas.

It is difficult to accept the diagnosis of ASD

Because they are unaware of ASD, the news of the diagnosis has a great impact, sometimes negative, bringing feelings of frustration and denial, making them have doubts about the diagnosis, thus hiding this fact from other family members out of fear, which makes the acceptance process difficult.

"It was really hard, we were devastated, we didn't know what autism was, I think that maybe that also contributed to making us even more desperate." (P7)
"For me, the mother, I suffered a lot, I didn't accept it, it took me about two years to accept it, you know, for about three months I just cried." (P4)
"It was really shocking at the time, it was a shock at the time, you don't want to believe it because you say it like that, is it really true? What, right? It was hard to accept it at first, you ask yourself 'why God, why with me?' Until you start to accept it. For him (husband) it was really hard to accept it, at first he didn't want to tell people, we told the family when he was about three and a half years old." (P1)

Even though they are aware that their child has a disability, family members look for positive aspects of their child's development to deny the diagnosis. Most of the time, acceptance is more difficult for parents, putting a burden on the mother of the autistic child, who, in addition to dealing with the grief of her healthy child, needs to support the father figure in accepting the diagnosis.

"It was very Fathernful, I cried and my husband cried. It took two to three months for us to adapt, for my husband it was worse, he would go into the room and cry [...] he didn't want to believe it, he didn't want it to sink in, [...] I suffered a lot, I was sad, we didn't leave the house anymore, I didn't want to go out, I didn't know how to deal with him." (P5)
"It was a punch in the stomach, I lost my footing, at first I tried to deny it, it's not that I tried to deny it completely, I tried to cover it up, I tried to find something that was normal for him and I always told the psychiatrist, he does this, he does that and she said: He has ASD... it was something that hurt my soul because he was a long-awaited child, we spent two years trying [...] it was very difficult for my husband, now that my husband is recovering [...] my husband became kind of depressed, inert, he felt really bad and it's very difficult for him [...] he felt worse than me." (P3)

The process of acceptance can be very difficult when the diagnosis is finalized, however, it can also be seen as a feeling of liberation, as finally discovering what the child has means that they can seek appropriate treatment for the pathology, without exempting themselves from the process of denial.

"We didn't receive the news as a shock, but rather as a relief, because we knew what our son really had." (P8)

Seeking knowledge to better understand the diagnosis

The expectation of the idealized child ceases to exist and gives way to the real child who needs special care, so family members seek knowledge about Autism Spectrum Disorder, and at this time, the support of health professionals proves to be very important, providing a basis for the necessary care and family restructuring.

"As my husband, family and I became more educated on the subject and received help from professionals in the field, things started to flow and are getting better." (P9)
"We started researching everything about autism." (P10)

When family members go through the process of denial and accept the diagnosis of ASD, they try to make up for all the time lost without treatment, first seeking help from the professional who diagnosed the child to improve their knowledge on the subject, and secondly, information on social media, literature and NGOs, thus having access to life stories of people who live with ASD and their family members. In this way, it is possible to find therapies that help in the development of the autistic child, improving the prospects for the future life of their children.

"We asked the pediatrician to tell us what we should do, and from there we started looking for treatments [...] we rolled up our sleeves and started racing against time to try to help him." (P7)
"And when we realized that no matter the

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answer, nothing would change, and so we started looking for information, knowledge, and therapies." (P6)
"I watched a movie called Hugo's Story [...] it tells stories about autistic teenagers and adults. Sports are wonderful, swimming, and I'm planning on getting him into jiu-jitsu [...] there's no point in taking him to the best specialist and not encouraging your child at home." (P3)

Changing family social life

The burden on mothers is greater than that on other family members, and the vast majority report having to leave their jobs or reduce their working hours to meet the needs of their children and other family members. This is because daily therapies change a large part of the routine when everything else is adjusted around them.

"I quit my job [...] I went to take care of this child to help him develop [...] I had been working for 8 years, I have a postgraduate degree. Everything changed, financially it changed drastically, our standard of living dropped 80% [...] when we left, our routine changed a little, I never stopped going to places, but I've already returned home, but I still try to go and I'm surprised by him". (P4)
"That's one of the things that was difficult at first, because the routine is more demanding than that of a normal mother [...] I try to divide my time between him and my things, which is my job". (P1)
"To this day I haven't been able to go back to work and study, I'm the one who keeps him busy, I'm the one who takes him to therapy. Our dreams change, things change." (P2)

Changes in social life are inevitable after diagnosis, bringing changes to the social activities that were previously carried out, since the family member with ASD does not meet the expectations that society imposes. Thus, parents often feel excluded when living with other families whose children do not have a diagnosis of autism spectrum disorder.

"I tell my husband, the world is no longer about family at the weekend barbecue, our world now is made up of the friendships we create with the parents and other special children who bring us much, much more richness, bring us together." (P3)

Life experience brings continuous observation to the family member with ASD. Family members know when the child with autism is no longer comfortable and what bothers them. The vast majority report that they no longer stay in a certain place for as long as before, they avoid certain places and return home when they notice that the child is already showing signs of discomfort.

"We couldn't go to birthday parties, we couldn't go to the supermarket, the cafeteria, anywhere because he would scream, he wouldn't sit down." (P5)
"When we got there, no child would socialize, no child would come near him, all the children were his age... I don't know if I would go to a child's party again if I wasn't autistic, I don't want to go through that again." (P2)
"We avoided certain situations and places for a long time because of the noise, too much information, balloons, and New Year's fireworks, it's still overwhelming." (P6)
"...it took a long time for family members to accept him, there was prejudice and a lack of awareness in society when they saw a crisis or inappropriate behavior in a public place." (P8)
"When we found out he was autistic, it brought the family closer together, because now we have another mission to help him live a life without needing too much help and, if possible, independently." (P10)

The presence of a child with ASD can lead the family to social isolation due to the prejudice they feel, but it can also be a factor of unity, as if the family joined forces for mutual support and to support the child in the challenges that the condition will bring.

DISCUSSION

The diagnosis of ASD awakens in parents a feeling of suffering in the face of the unknown and the impotence of resolving their child's condition, going through several phases until acceptance, these phases include feelings of shame, anger, lack of motivation and sadness. [18]

The couple plans their children to have a healthy life with a projection of adulthood with independence and the expectation of a naturally typical individual. [19] In this sense, the diagnosis of ASD brings, from the beginning of the diagnosis, feelings of mourning for knowing that their expectations will not be fully met as planned, thus, setting goals again for the family member who has just had their diagnosis revealed brings momentary difficulty in acceptance. [19]

For the family to have acceptance after the diagnosis, it is necessary to experience the mourning of the idealization and expectations created for the child, so that, over time, the mourning gives way to new planning with the new reality. This process occurs in several phases, contemplating the initial shock of the diagnosis, demonstrating fear, guilt, anger and frustration in the face of the feeling of not being able to do anything for the family member. [9,18] This mourning varies according to each family, based on their personality formation and concepts, and may therefore have a longer or shorter mourning period. [20]

Programs that provide information about ASD and emotional support are important to help with acceptance and well-being for this family. They help promote educational health by providing the necessary support for the family member. [9]

The first guidelines for seeking therapies generally come from the doctor who diagnosed the ASD, usually the doctor himself refers the child to the most common therapies, such as speech therapy, occupational therapy, Applied Behavior Analysis (ABA), physiotherapy and adaptive sports. [13] It may also be recommended that the child be monitored by an NGO specializing in care for children with ASD.

These follow-ups are extremely important for training families to care for their children. Studies show that training parents

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to apply some therapies at home has a great advantage, since they know the behaviors of their family member and their difficulties, and can pass on the knowledge acquired to close family members who live with the child.[21]

The family's search for knowledge about the child's condition arises in the face of many unanswered questions, generated by the child's behavior and by common doubts about attitudes taken in everyday situations; health professionals must focus their care on the child and the family, verifying the level of knowledge that the family has and sharing their knowledge about ASD, helping the family to better cope with the diagnosis.[9]

The family routine changes after the arrival of a child with ASD, especially mothers, who are physically and mentally overloaded in daily activities with high levels of stress and poor quality of life for themselves and the family, which can lead to maternal depression, negatively affecting both mother and child.[22-23] Social isolation and lack of leisure activities exacerbate these stress and depression symptoms in these mothers.

There is still little understanding on the part of society, which makes it difficult for these families to integrate into social life. As a result, mothers report their experiences in relation to people's approach, looks, attitudes, prejudice, judgment and, as a result, they report difficulty in leaving the house. Families of children with ASD report social isolation due to discriminatory attitudes and non-acceptance of behaviors. This may occur due to the population's lack of knowledge and misunderstanding of the disease.[9]

Lack of information, prejudice and discrimination can be understood as an attitude resulting from fear, while distancing is caused by the stigma of rejecting everything that is unknown and different, especially people. Thus, families feel excluded from society, suffer and possibly become depressed.[9, 24]

CONCLUSION

The diagnosis of Autism Spectrum Disorder results in changes to the entire family life, bringing consolidation of knowledge for social coping and adaptation of the child's life, thus seeking to maintain their well-being.

Therefore, it is necessary for the family to make an effort to adapt to the new reality, and with all these changes in the family routine and the emergence of difficulties, many mothers have reduced their workload or left their jobs to dedicate themselves to caring for their children. Families struggle to protect and not expose the child, and emphasize the importance of therapies for the development of their children.

Society's intolerance in the face of a crisis in a public environment, strange looks and negative speeches regarding education were also relevant points observed in this study, requiring greater awareness of the population regarding special children and their families.

Limiting factors in this study include the population from a single location, the time of the participants as a hindrance in conducting the interviews, and the monitoring of the children by a multidisciplinary team, as this support clearly contributes to effective monitoring of the children, resulting in better acceptance and adaptation of these families. Other studies should be conducted in other locations and with families with less access to health care.

Social support is essential to maintain health, providing the knowledge and support necessary for the well-being and quality of life of families. Nurses involved in the care of children with ASD are links in guiding these families, as well as in guidance and support, seeking greater progress in the development of these children and better adaptation of these families to care.

TABLE 1 - CHARACTERIZATION OF RESEARCH PARTICIPANTS

PARTICIPANT	FAMILY INCOME	MOTHER'S PROFESSION	WITH WHOM THE CHILD LIVES	FAMILY AGE	RELIGION	DIAGNOSTIC TIME
01	N/A	Nutritionist	Parents	Mother 30 Father 47	Evangélica	3 anos
02	5.000	Housewife	Parents	Mother 32 Father 35	Católica	3 anos
03	40.000	Businesswoman	Parents and sister	Mother 42 Father 35 Sister 16	Católica/ Espírita	3 anos
04	2.500	Housewife	Parents	Mother 35 Father 38	Evangélica	5 anos
05	2.700	Housewife	Parents, grandparents and nieces	Mother 40 Father 36	Evangélica	4anos
06	1.300	Inspector	Parents and sister	Mother 38 Father Sister	Católica	5 anos
07	7.000	Lawyer	Parents	Mother 36 Father 39	Católica	5 anos
08	6.000	Teacher	Parents	Mother 36 Father 36	Budista	4anos
09	ND	IT Professional	Parents and brother	Mother 34 Father 34 Brother 5	Católica/ Espírita	3 anos
10	ND	Pharmaceutical	Parents, grandparents and brother	Mother 46 Father 46 Brother 16 Grandmother 72	Budista	3 anos

SOURCE: The authors, 2020.

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