

## **Social exclusion and inclusion: perception of family members living with a person with autism spectrum disorder**

**Exclusão-inclusão social: percepção de familiares que convivem com pessoa com transtorno do espectro autista**

**Exclusión-inclusión social: percepción de los familiares que conviven con una persona con trastorno del espectro autista**

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### **Abstract**

**Objective:** Identify evidence of social inclusion and exclusion perceived by family members, due to living with a person diagnosed with Autism Spectrum Disorder (ASD). **Methodology:** The study was conducted following a qualitative approach, in which five families that live with a person diagnosed with ASD were part of our analysis, involving fathers (2), mothers (5), brothers (2) and grandmother (1). Data collection was carried out through recorded interviews, using the Critical Incident Technique, and data were organized using Bardin's thematic content analysis. **Results:** Two thematic categories emerged: "The context of autistic life and its adversities facing stigma and exclusion" and "A positive view of Autism Spectrum Disorder." The first addresses the adversities and difficulties faced in identifying the disorder and in the process of family adaptability. This category also takes into consideration society's and family's lack of knowledge about ASD, which leads to social exclusion. The second category exhibits lessons learned while living with a person diagnosed with ASD. **Conclusion:** Furthermore, it portrays the adaptation and growth occurred in intrafamily relationships. Therefore, daily living with a person with ASD is characterized by adversity, stigma and social exclusion. However, it also distinguishes the resilience and overcoming of family members.

**Keywords:** Autistic spectrum disorder; Family; Social exclusion; Social stigma; Life change events.

### **Resumo**

**Objetivo:** Identificar evidências de inclusão e exclusão sociais percebidas por membros familiares, devido à convivência com pessoa com diagnóstico de Transtorno do Espectro Autista (TEA). **Metodologia:** Estudo com abordagem qualitativa, no qual fizeram parte cinco famílias que convivem com pessoa com diagnóstico de TEA, sendo pais (2), mães (5), irmãos (2) e avó (1). A coleta de dados foi por meio de entrevista, gravada, utilizando-se a Técnica do Incidente Crítico. Os dados foram organizados utilizando-se à análise de conteúdo temática de Bardin. **Resultados:** Emergiram duas categorias temáticas: "O contexto de vida do autista e suas adversidades diante do estigma e da exclusão" e "Um olhar positivo para o Transtorno do Espectro do Autismo". A primeira aborda as adversidades e dificuldades enfrentadas na identificação do transtorno e no processo de adaptabilidade familiar; a falta de conhecimento a respeito do TEA pela sociedade, e de membros familiares, que propiciam a ações de exclusão social. A segunda exibe o aprendizado na convivência com o TEA, a adaptabilidade e o crescimento nas relações intrafamiliares. **Conclusão:** Destarte, o convívio cotidiano com uma pessoa com TEA caracteriza-se com adversidades, estigma e a exclusão social. Contudo, também, distingue a resiliência e a superação dos familiares.

**Palavras-chave:** Transtorno do espectro autista; Família; Exclusão social; Estigma social; Experiências de vida.

### **Resumen**

**Objetivo:** Identificar evidencias de inclusión y exclusión social percibidas por los familiares, debido a la convivencia con una persona diagnosticada con Trastorno del Espectro Autista (TEA). **Metodología:** El estudio se realizó

siguiendo un enfoque cualitativo, en el que cinco familias que conviven con una persona diagnosticada con TEA fueron parte de nuestro análisis, involucrando a padres (2), madres (5), hermanos (2) y abuela (1). La recolección de datos se realizó a través de entrevistas grabadas, utilizando la Técnica del Incidente Crítico, y los datos fueron organizados utilizando el análisis de contenido temático de Bardin. Resultados: Dos categorías temáticas surgieron: “El contexto de la vida autista y sus adversidades frente al estigma y la exclusión” y “Una visión positiva del Trastorno del Espectro Autista”. La primera aborda las adversidades y dificultades enfrentadas en la identificación del trastorno y en el proceso de adaptabilidad familiar. Esta categoría también toma en cuenta el desconocimiento de la sociedad y la familia sobre los TEA, lo que conduce a la exclusión social. La segunda categoría exhibe las lecciones aprendidas durante la convivencia con una persona diagnosticada con TEA. Conclusión: Además, retrata la adaptación y el crecimiento ocurrido en por lo tanto, la convivencia con una persona con TEA se caracteriza por la adversidad, el estigma y la exclusión social, pero también distingue la resiliencia y superación de los familiares.

**Palabras clave:** Trastorno del espectro autista; Familia; Exclusión social; Estigma social; Eventos de cambio de vida.

## 1. Introduction

Autism Spectrum Disorder (ASD) has been considered a neurodevelopmental disorder, represented by marked impairment in several areas of development, mainly due to changes in behavior, communication deficits and imbalance in social interaction. In communication and social interaction, changes are manifested with restrictions in socio-emotional relationships, in the predominant use of non-verbal communication behaviors (gestures, look, body language) and, in the limitation to understand, initiate and maintain social relationships. ASD is characterized by a complex set of behaviors, interests or restricted and repetitive activities that interfere in a harmful way in the normal development of individuals (APA - American Psychiatric Association, 2013).

Even nowadays, Autism Spectrum Disorder has been looked at inadequately by numerous health professionals and by myriad people in society. Thus, living with a person who has ASD is characterized by facing adversities, such as the lack of preparation of many health professionals when it comes to identifying the disorder. This inability forces the parents to go through an arduous path until they get the diagnosis. Furthermore, society's limited knowledge on the subject leads to stigma towards autistic people and their families. Often, autistic individuals are deprived of their liberty, in the family or community. They suffer discrimination and are vulnerable to different forms of violence (Reddy et al., 2019; ABRAÇA, 2016).

Analyzing studies that address ASD, it appears that the person with this disorder has neurobehavioral profiles and similar emotional and social challenges anywhere in the world, whether in a developed or developing country. What establishes the difference in context, among others, is the culture, the economic factor and the public policies of each place which provide the care of the autistic and their family nucleus (Ardic, 2020; Bidaki & Jahangiri, 2019; Cloete & Obaigwa, 2019; Desiningrum et al., 2019; Derguy et al., 2018; Predescu & Şipoş, 2017; Chan & Lai, 2016; WHO - World Health Organization, 2013; Starr & Foy, 2012; Plumb, 2011).

In the literature, advances in studies focused on ASD can also be seen, with extensive information regarding, among others, the diagnosis, manifestations of the disorder, treatment, interventions, and validation of instruments to identify signs of autism risk (Fadda & Cury, 2019). However, little has been explored regarding the issues of social exclusion and inclusion related to ASD.

Thus, the study aims to identify evidence of social inclusion and exclusion perceived by family members, due to living with a person diagnosed with Autism Spectrum Disorder.

## 2. Methodology

This study meets the objective of a broader project called “Process of Health, Disease and Social Exclusion”. The study was carried out in accordance with the international ethical standards established in the Declaration of Human Rights of Helsinki, with approval by the Standing Committee on Ethics in Research Involving Human Beings (COPEP) of the State

University of Maringá Brazil, CAAE: 26049514.7.0000.0104.

This work is characterized with a descriptive, exploratory character with a qualitative approach.

The research subjects were identified at the Parents and Friends of the Exceptional Organization - “Associação de Pais e Amigos dos Excepcionais” (APAE) located in a small town in southern Brazil. The APAE of this municipality had 70 students, five of whom, aged between 4 and 20 years, had the diagnosis of Autism Spectrum Disorder.

For the present study, the family members of these five people diagnosed with ASD who attended the association were considered. They agreed to participate in the research and signed the free and informed consent form (FICT).

The first contact with family members took place via telephone, provided by APAE, in which the day for a home visit was scheduled with the family. Signature of the informed consent was obtained first and then data collection was carried out.

Data collection was carried out through an interview, using the Critical Incident Technique (TIC) (Dela Coleta, 1974), supported by a semi-structured script, in which the interviewees reported, in detail, events/situations - positive or negative - that occurred due to living with a person diagnosed with ASD and that marked their life.

The interviews were carried out with family members who live with a person diagnosed with ASD. They were carried out at the respondents' homes, individually and in privacy, respecting the availability of the subjects. It is worth mentioning that two home visits were carried out in each family.

The interviews were recorded and later transcribed in full. For the organization of the collected data, thematic content analysis by Bardin (2016) was used and discussed in the theoretical frameworks available in the area of health and the like.

The collected data were used guaranteeing the anonymity of the subjects, and for this the families were characterized by colors, and the family members by letters, where F for father, M for mother, B for brother, S for sister, and G for grandmother.

## **2.1 Sample characterization**

Five families who live with a person diagnosed with ASD were part of this study, and the family members included fathers, mothers, siblings and grandmothers.

The Pink family is made up of a 14-year-old autistic teenager and his mother, who is a widow, retired and a housewife.

In the Blue family home, lives a 9-year-old child with ASD, a mother who works as a saleswoman, a father who is a civil servant and a brother who is a student.

The Red family consists of the grandmother who is retired, a four-year-old sister, the mother who is a civil servant and the 7-year-old autistic child. The grandmother takes care of the house and all the children.

The Yellow family, in which the autistic member is 20 years old, is composed of the mother who is a teacher, the father who works as a businessman, and the younger sister who is a student.

The Green family is constituted only by the 10-year-old autistic child and the mother, who works as a housekeeper, bearing all the family expenses alone. The child stays in school full-time so the mother can work.

It should be noted that the terms "ASD" and "Autism" are being used in this study as synonym.

In the data analysis, from the transcripts of the interviews, two thematic categories emerged: "the context of autistic life and its adversities in the face of stigma and exclusion" and "a positive view at Autism Spectrum Disorder".

## **3. Results**

### **3.1 Main category 1: The context of autistic life and its adversities in the face of stigma and exclusion**

In view of the main difficulties mentioned by family members, the anguish of perceiving the difference in behavior

and the effort needed to confirm the diagnosis of ASD is evident in the reports, revealing the difficulty that some health professionals have to identify the disorder:

*“My story is characteristic of those who have an autistic child. With many difficulties to reach the diagnosis, a lot of running after doctors, schools [...]” (BLUE-M).*

*“I fought hard to find out what she had. People are not prepared to make this diagnosis [...]” (RED-M).*

*“Since he was little, I've seen that he was different... I took him to several pediatricians and that's how the search for a diagnosis began...” (YELLOW-F).*

One of the main aspects unanimously revealed by all the families in this study is the importance of routine in day-to-day activities. The change in routine, with environments and people different from the usual, can trigger in the person with ASD the antisocial behaviors characteristic of the disorder, with excessive misunderstanding of society and even with inappropriate comments:

*“I already suffered a lot when he was younger [...] everything has to be the right way, he can't escape the routine, because then he gets angry, he doesn't like it” (BLUE-F).*

*“[...] she doesn't like it at all whenever anything changes, if something is different she gets angry, screams [...] one day a girl who was passing on the street was scared by how mad my daughter was and said: “A girl this old throwing a tantrum? If she was my daughter, I would slap her” [...]” (PINK-M).*

*“These days we went to another city by plane, he was scared of the airport, the size of the planes, the noise, the amount of people. He started screaming and jumping around, agitated; everyone looked, but no one said anything. When we got on the plane, he was still scared, so a passenger complained that this type of person shouldn't be allowed to get on a plane, because he disturbs the tranquility of the others passengers...” (YELLOW-M).*

It is observed in previous reports that society's lack of knowledge about ASD leads to actions of segregation, stigma and misunderstanding. This leads the family members of the person with autism to embarrassment. The following narratives clearly show the difficulties of autistic people before society in public places and the marginalization to which they and their families are subject.

The correlation between the features of ASD that literature presents us and the information from our data led us to the clear notice of the fixation towards objects and the antisocial behavior of the autistic person, which causes strangeness to the community. When people do not have knowledge about the disorder, they can have inappropriate and stigmatizing attitudes and insinuations:

*“[...] we went to a friend's daughter's birthday [...] he took a straw, and stared, looked, looked, looked at it like it was a jewel. Then another mother who was at the table with us, with a pity face, said that my son had a problem [...]. I got up and left... it bothered me a lot [...]” (YELLOW-M).*

*“Once we were at a friend's house and he wanted to leave, so he started to run, running non-stop around the house. Nobody made him stop. People who didn't know him found it strange and kept asking what he had. My mother would explain that he was a special child, then they would make a pity face, like they were in pain...” (YELLOW-S).*

*“In a store there was that ball pit and the saleswomen kept insisting for him to play, and he would stay quiet, with his eyes downcast, pulling me to leave. Then the saleswoman asked me if he was disabled. I explained that he was autistic*

*and that the situation bothered him. Then I saw her commenting with the other salespeople, as if she had just met an alien..." (BLUE-M).*

Another characteristic of ASD is the unpredictable behavior, sometimes aggressive, as experienced by one of the study subjects:

*"[...] when she argues with/dislikes someone she wants to scratch, hit [...] things have to be the way she wants. People keep looking, I suppose they look and think "this girl is not normal", it makes me sad [...]" (RED-G).*

In the experience of family members, situations were shown in which the presence of a family member with ASD led to prejudice, stigmatization and clear social exclusion:

*"I see when we go out, people often find him strange: too quiet, with his head down, or he stares somewhere, and people keep commenting..." (BLUE-F).*

*"People are unaware of autism, they have no information about what it is [...] When you have a child like that, it kind of shocks people, because they don't know what the disorder is, the complexity. They think your child is behaving strangely, sometimes they say: what a strange child!" (YELLOW-F).*

The narratives reveal the family members' recognition of prejudice and feelings of misfortune, of pity, that the autistic person and their own family experience due to the disorder. This reveals the social stigma that this disease carries.

*"[...] after I started to see how difficult the world is for him, I started to realize that there is a lot of difficulty, prejudice. Not only for the autistic but for the family as well [...]" (BLUE-M).*

In the reports, we also observed the worries of siblings of the person with ASD:

*"People find the behavior strange, but that's a lack of information, they feel sorry... what I think is the worst of all is feeling sorry for him. [...] I'm not telling you it's easy [...]. I see how much my parents fight for Blue to have a better quality of life, [...] they live in function of his needs [...]" (BLUE-B).*

In addition to the brother, other interviewees expressed the need for full-time care for the autistic, noting that families organize all their days with the person with ASD as the central axis:

*"We've been through a lot of difficulties. [...] we kind of hold our lives because of it. We couldn't, for example, go to the beach because there were always so many questions [...]" (BLUE-F).*

*"[...] it's not easy, because it requires a lot of time and care from me" (RED-M).*

In the reports of the interviewees, the social withdrawal to which families are subject is evident, due to the presence of a family member with ASD:

*"[...] I don't leave the house much with her, I only go home to school [...]" (PINK-M). "Life is hard. Because of her problem, we can't leave the house much [...]" (RED-G).*

*“He does not live in society, we prefer not even to expose him in situations that we know he will not like [...]” (BLUE-B).*

In the narratives, in addition to the isolation of families from society due to the disorder, we found stigma and exclusion within the family itself:

*“My father, her grandfather, has prejudice against her. Since when we found out she had this problem, he started to treat her in a different way, avoiding her [...] there are people in the family who don't come home because of her. My brother, for example, pays little attention, he never comes to see us, and if he comes, he doesn't even drink water, it seems he's disgusted because of it... I was really sad, because it's my family, but then I got used to it, time passes, it was just her and I at home and so we go on...” (PINK-M).*

In the following report, it is clear that the brother totally excludes the autistic person from his life and, in view of this, the mother reveals immense concern about who will take care of the autistic person when she dies:

*“It's not easy, my life revolves around Rosa. I'm only afraid of what will happen after I die, what will happen to Rosa {CRYING} [...]. The brother who lives next door doesn't even care. She only has me to take care of her. And as I am already old, I have this concern in my head [...]. I think all day about these things, I think I'm even sick because of it” (PINK-M).*

### **3.2 Main category 2: A positive view at autism spectrum disorder**

In the report, it is possible to identify the positive reception that people, even with a simple “hello”, are able to offer. It shows that a simple gesture can have a positive impact on those which deal with the disorder on a daily basis:

*“I walk her to school every day [...] On the way to school there was a woman who was always sweeping the sidewalk when I passed with granddaughter. Then the women started saying hi, playing with her [...] I explained that she had problems... the women kept saying hi, trying to get closer to the girl” (RED-G).*

The testimonies of the study participants reveal the difficulties experienced and progressions developed by family members when living with a person who has ASD. They state that over time the trials became a reason for the family to overcome:

*“Despite all the challenges that I face while living with him, I am grateful for having him with me today. He's not a normal child, but he loves with his eyes, he doesn't look us in the eye, but I feel his love. I'm privileged to be his mother [...] He made me a better person. When we have a special child, we see the world differently...” (BLUE-M).*

*“I am very optimistic [...] She is a gift in my life. With her I learned that I have the strength to fight and that I can overcome...” (RED-M).*

*“Despite the difficulties, I know that I have a wonderful son, that I have a lot of love for him and he for me...” (BLUE-F).*

*“Everything has its good side in life. I learned a lot from him, because it's very easy to love a child who smiles at everyone, plays, and makes jokes. When your child doesn't even look you in the eye and you still love him, that's*



*unconditional love. I learned that he loves in his own way, and it's not up to us to try to fix it that way. I learned to respect life with him... My joy is to see him evolving every day. Evolution is slow but it happens and that brings me satisfaction..." (YELLOW-M).*

*"The love I have for him is very strong... he has suffered prejudice, yes, but many people have also helped. Nowadays I see his problem as being positive in my life..." (GREEN-M).*

Adversities, segregation, stigma, social exclusion, but also the resilience and overcoming of family members who live daily with a person with ASD are apprehended in the reports.

## **4. Discussion**

### **4.1 The context of autistic life and its adversities in the face of stigma and exclusion**

The singularities that distinguish the life context of each individual with autism allow us to interpret ASD as a plural phenomenon (Lima & Couto, 2020). This diversity configures the search for the identification of the disorder as a period marked by uncertainties and questions, where the interviewees of our study were unanimous in affirming that, once differences were observed in the child, they had to go through several doctors and specialists in order to unveil the phenomenon and obtain the diagnosis of ASD.

As revealed in the speeches, the search for a diagnosis is characterized as a journey of negative experiences and full of contradictions, marked by a period of inaccuracies, a long search through diversified services to obtain an answer (Lima & Couto, 2020; Aguiar & Pondé, 2020; Reddy et al., 2019; Constantinidis et al., 2018; Ribeiro et al, 2017).

The lack of early contact in academic training and the insufficient training of health professionals regarding mental disorders are presented as possible factors that contribute to the damage in the diagnosis and in the direction of care in these situations, as in the case of ASD (Carvalho et al. al, 2021; Menezes Neto et al, 2021).

The literature points out that most health professionals recognize themselves as unprepared to communicate a difficult diagnosis of the child to the parents, as is the case with ASD. And parents, in general, feel deprived to receive such a diagnosis. Therefore, the way in which this diagnosis is given has to be skillfully arranged and must be individualized for each situation (Aguiar & Pondé, 2020).

Regardless of the particularity of each family member, the diagnostic confirmation of ASD triggers changes in household dynamics, daily tasks and routines. Adaptations in the family context are carried out exclusively to support and meet the care needs of the autistic person (Portes & Vieira, 2020; Constantinidis et al., 2018).

Supporting findings from previous studies (Fernandes et al., 2021; Portes & Vieira, 2020; Fadda & Cury, 2019; Constantinidis et al., 2018), family members cite the adequacy of their own behavior in relation to the autistic as the main challenge. The interviews of our study, carried out in the family environment, allowed us to confirm the dependence of the child with ASD, causing parents, especially, to stop performing functions that were routine before having an autistic child. For example, it was normal and easy to leave the house, and now with the presence of TEA in the group, a simple exit needs planning.

As observed in studies, everything revolves around the person with ASD, and the need for the family to completely reorganize their life. However, it is still possible to achieve a balance in daily practices. For this, it is essential to create a routine, with determined times for each task, and to prepare the autistic person for changes in routines and outings. The implementation of routines will allow the autistic person greater predictability of daily tasks, avoiding unstable, explosive and anxiety behaviors. That is, the systematization of activities helps to attenuate feelings that naturally can lead to emotional disorder due to the ASD and avoid potentially painful situations for the autistic and their family (Fernandes et al., 2021; Reddy

et al., 2019).

With the purpose of alleviating the possible difficulties, the overload in the daily care and the suffering that may arise in the family group with the presence of the ASD, the guidance for the establishment of rules is a fundamental item that must be approached by the professionals who work with people affected by the ASD. The importance of the active participation of the autistic person and his/her family in the elaboration of the proposal of such practices is highlighted. When guiding the elaboration of routines, professionals must consider the contextualization of the different cultural, economic, social realities of each family nucleus (Fernandes et al., 2021; Machado, 2019).

Characteristics of the person who has ASD, exposed in the literature and also corroborated with our reports, reveals that the vast majority of autistics present repetitive, self-injurious or aggressive behaviors that commonly make it difficult for families to participate in public places, generating a process of isolation and social exclusion (Segeren & Françoço, 2014).

The present study is in agreement with another research (Ferreira & Smeha, 2018). Such research exposes that psychomotor agitation, screams, aggression, characteristic behaviors of the disorder, in many moments are difficult to be controlled. And, when they occur in a public environment, as evidenced in our reports - buses, stores, school trips, planes, supermarkets, bookstores - cause anxiety, embarrassment and concern on the part of parents and family members.

Therefore, since the actions caused by the disorder are a "box full of surprises", the concern of parents with people's prejudice in the face of unpredictable autistic behaviors becomes relevant (Ferreira & Smeha, 2018).

It is important for health professionals to consider that behavioral problems, in particular, greater emotional difficulties and less prosocial behaviors demand comprehensive care models, aimed at the person with ASD and their family. With the autistic, the professional must seek to enable the child to deal with their difficulties and maintain control of emotions, favoring their development. Considering the family members, the professional needs to develop in the caregivers the attention to the singularity, in which they will be able to interpret in the person who has ASD the discomfort or annoyance that is presented before noise, changing routines, approaching new spaces and social practices or different people and environments. These interpretations skills will be obtained by reading and by taking into account the signs revealed in the behavior of isolation, agitation and/or aggressiveness. Thereby, it is possible to promote greater well-being in the family group (Mira et al., 2019; Mapelli et al., 2018).

The present study clearly demonstrates adverse situations that family members experience socially due to ASD. Social behaviors that reveal echoed feelings of pity, prejudice, rejection or even looking at the autistic person differently, mobilize in the caring family the desire to protect their loved one further.

A phenomenon also observed in the previous literature admits that the inclusion of people with ASD in society becomes complex due to the behaviors of exclusion and prejudice that reflect scenarios of contempt and rejection in different social environments (Mapelli et al., 2018).

In this sense, studies have revealed that the labeling and the stigma towards the person with ASD, reinforced in society, generally generates effects that are not easily forgotten by their family members. That is, the look thrown by another person is a factor that influences the experience. Furthermore, realizing that people are uncomfortable, with aversion, in the presence of the autistic person is felt by family members as a gesture of discrimination (Balestro & Fernandes, 2012; Cezar & Smeha, 2011).

In agreement with another study, the siblings of the autistic people interviewed indicated their apprehension in the face of the stigma and overload that families are forced to face. The sibling of people with autism may face mixed feelings, from shame to an interest in protecting and helping care in order to ease the burden on parents (Anjos & Morais, 2021).

Therefore, it is important that parents and professionals who deal with children with disorders pay attention to siblings, as there may be aspects of living with a sibling with ASD that affect social life, such as the feeling of stigmatization.



In this sense, taking a holistic approach to meeting the psychosocial needs of parents can facilitate the adjustment of siblings (Chan & Lai, 2016).

The study reports also state similar challenges cited in other research (Predescu & Şipoş, 2017): having a child who needs special care triggers a process that takes less time for parents to attend to their own needs.

Our reports reiterate that the presence of a family member diagnosed with ASD promotes losses and impoverishment of social, affective and professional life, where the entire daily life of families is focused on the child or adolescent with autism. The adversities encountered by caregivers come usually from difficult and unstable ASD behaviors, which regularly lead to isolation from the family circle. Social isolation can be considered as a means of protecting the autistic from the negative behavior of society. Thus, at the same time that family members suffer from social isolation, they are bitter with the stigma and intra and extra-family exclusion that their loved ones are prone to due to ASD (Lima & Couto, 2020; Bianchi & Jurado, 2019; Cloete & Obaigwa, 2019; Constantinidis et al., 2018).

It is known that family and friends are an essential support component in the adaptation and adjustment of the family nucleus that lives daily with a member with ASD. However, some families may face prejudice and stigma resulting from autism, where the help of extended family members, and people who were considered friends, is not present. In this sense, confirming our study, research reveals that there are family members of autistic people who perceive that “rejection starts at home” (Anjos & Morais, 2021; Cloete & Obaigwa, 2019; Ferreira & Smeha, 2018; Pereira et al., 2018; Constantinidis et al., 2018).

Analyzing our reports with the literature, it is observed that the characteristic behaviors of the disorder's dysfunction, manifested when the subject with ASD is uncomfortable, annoyed or rejected in society, determine the presence of the family in social environments. Generally, the family prefers to escape from the universe where the child feels uncomfortable or is despised, as prejudice is experienced with suffering, both in the intra and extra-family spheres (Mapelli et al., 2018).

The importance of family support, or lack of it, is shown in the report of one of the mothers interviewed, where the stress in the concern of who will take care of the autistic person when she dies is revealed. This scenario is also found in the literature (Reddy et al., 2019).

Parents, as primary caregivers of children with developmental problems, such as ASD, are faced with sui generis challenges. Thus, they tend to have their quality of life impaired. This leads them to greater vulnerability to stress when compared to parents of children with other disabilities. Such parental stress can affect care and family relationships. In this context, the health professional must seek the implementation of care considering the members and the family function, always aiming to promote resilience, psychological well-being and, consequently, the quality of life of the nucleus (Desiningrum et al., 2019; Derguy et al., 2018; Estrem et al., 2018; Gallo et al., 2019; Mitchell et al., 2018; Pratt & Skelton, 2018; Lu et al., 2017).

#### **4.2 A positive view at autism spectrum disorder**

In the analysis of the second category, it appears that the difficulties and concerns of family members in the process of acceptance and adaptation initially generated many doubts and questions. However, over time, the adaptability of family members regarding the autistic child's behaviors was successful.

The literature strengthens our findings, shown in the reports, that some family members integrate the challenges of caring for the person with ASD in a positive way, maintaining a hopeful mindset (Ekas et al., 2016). In this sense, the presence of ASD can initially be characterized by feelings of vulnerability, exhaustion, helplessness, but with coexistence, new paths emerge, forming a relationship with possibilities and growth (Fadda & Cury, 2019).

In our study, parents revealed concern, doubts and anxiety regarding the future of their child diagnosed with ASD.

However, according to previous research, these anxieties can be alleviated over time, when parents of children and adolescents with autism are acquiring high levels of psychological well-being. This psychological quality can occur from the moment the family members achieve an appropriation in the role of caring. This accommodation is mainly related to the development of more effective strategies for care, over time, for and from the person with ASD (Segeren & Françoze, 2014).

Phenomenon observed in the literature, and which emerges from the reports, evidences the affection, kindness, gratitude, learning, potency, empowerment of the family that cares and loves. This reveals the good side of living with the person who has the diagnosis of ASD. However, a study points out that the feelings of family members who cohabit with a member with autism can vary along with acceptance, denial and pride. The expression “autistic pride” has spread around the world through an initiative of the North American association Aspies for Freedom (AFF) which, in 2005, celebrated, for the first time, and established June 18 as Autistic Pride Day (Lima & Couto, 2020; Ortega, 2009).

The adversities that the family are facing form an element that is evident in the reports. However, the adaptation of the whole family in living with a person with ASD highlights the overcoming and the contentment of having the opportunity to live with the autistic person. In this sense, the literature states that the presence of a member with ASD in the family can lead to a positive adaptation in the group. This affirmative adjustment occurs when the dysfunction is approached as a growth and learning experience, not stereotyped as a misfortune. Nevertheless, it must be considered that each family is peculiar and seeks to develop its own dynamics of functioning, with its different instruments and artifices, to face the misfortunes (Anjos & Morais, 2021).

## **5. Conclusion**

Thus, we emphasize that living with a person with autism creates many challenges for families, especially in economic, social and emotional aspects. Due to the fact that people with disabilities are often invisible in their needs, the qualification of professionals capable of working with ASD, who have a vision of the family environment in the context of autism, becomes a fundamental condition. Furthermore, mainly, the inclusion of these subjects as equal members in society is also a fundamental condition.

Our study showed the adversities emerged when living with a person who has ASD. However, it also revealed adaptability, learning in coexistence, growth in intrafamily relationships and contentment with the coexistence of the autistic in the family nucleus.

This study was developed in a small city, with a small number of participants but we chose these carefully based on their high level of representability for our subject. The reports revealed a wealth of information, which allow us to contribute to stimulating advances in the care of the person with ASD and their family.

We recommend the development of studies that seek to highlight the hermeticism of Autism Spectrum Disorder in its various contexts - family, society, academic and professional training - which may contribute, among others, to the reduction of the stigma, to the implementation of public policies, and to health care regarding the mental health of the population.

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## References

- Aguiar, M. C. M. & Pondé, M. P. (2020). Autism: impact of the diagnosis in the parentes. *J Bras Psiquiatr.*, 69(3), 149-155.
- American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders*. 5th ed. Arlington, VA: American Psychiatric Publishing.
- Anjos, B. B. & Morais, N. A. (2021). Experiences of families with autistic children: an integrative literature review. *Cienc. Psicol.*, 15(1), e-2347.
- Ardic, A. (2020). Relationship between parental burnout level and perceived social support levels of parents of children with Autism Spectrum Disorder. *Int J Educ Method.*, 6(3), 533-543.
- Balestro, J. I. & Fernandes, F. D. M. (2012). Questionnaire about communicative difficulties perceived by parents of children of the autism spectrum. *Rev Soc Bras Fonoaudiol.*, 17(3), 279-286.
- Bardin, L. (2016). *Content analysis*. Translated by Reto, L. A. & Pinheiro, A. São Paulo: 70th ed.
- Bianchi, E. & Jurado, S. R. (2019). Biomedicalization of times: therapies, biosocialities and daily cares in children with ASD diagnostic in Buenos Aires. *Saude Soc.*, 28(1), 92-106.
- Bidaki, Z. Z. & Jahangiri, M. M. (2019). Effectiveness of acceptance and commitment-based therapy on psychological flexibility among mothers with autistic children. *J Arak Uni Med Sci.*, 21(7), 41-47.
- Brazilian Association for Action for the Rights of Autistic Persons (ABRAÇA). (2016). *Manifesto: I am autistic, I have the right to my own body*. Brazilian Association for Action for the Rights of People with Autism.
- Carvalho, L. S.; Santana, I. G. L.; Freitas, C. K. A. C.; Medeiros, A. de A.; Santos, A. de J.; Santos, B. G. de A.; Barreiro, M. do S. C.; Melo, M. S.; Santos, T. S.; Silva, G. M. Evaluation of the opinion of undergraduate students in the health area regarding people with mental disorders. *Research, Society and Development*, [S. l.], v. 10, n. 14, p. e269101422134, 2021. DOI: 10.33448/rsd-v10i14.22134. <https://rsdjournal.org/index.php/rsd/article/view/22134>. Acesso em: 15 sep. 2022.
- Chan, J. Y. & Lai, K. Y. (2016). Psychological adjustment of siblings of children with autism spectrum disorder in Hong Kong. *East Asian Arch Psychiatry*, 26(4), 141-147.
- Cloete, L. G. & Obaigwa, E. O. (2019). Lived experiences of caregivers of children with autism spectrum disorder in Kenya. *Afr J Disabil*, 8, 435-443.
- Constantinidis, T. C.; Silva, L. C. & Ribeiro, M. C. C. (2018). "Everyone Wants To Have a Perfect Child": Being Mother of Children with Autism. *Psico-USF*, 23(1), 47-58.
- Dela Coleta, J. A. (1974). The critical incident technique: applications and results. *Arq. Bras. Psic. Aplic.*, 26(2), 35-58.
- Derguy, C.; Roux, S.; Portex, M. & M'bailara K. (2018). An ecological exploration of individual, family, and environmental contributions to parental quality of life in autism. *Psychiat Res.*, 268, 87-93.
- Desiningrum, D. R.; Suminar, D. R. & Surjaningrum, E. R. (2019). Psychological well-being among mothers of children with autism spectrum disorder: the role of family function. *Humanitas*, 16(2), 106-115.
- Ekas, N. V.; Pruitt, M. M. & McKay, E. (2016). Hope, social relations, and depressive symptoms in mothers of children with autism spectrum disorder. *Res Autism Spect Dis.*, 29(30), 8-18.
- Estrem, H. H.; Thoyre, S. M.; Knafl, K. A.; Pados, B. F. & Van Riper, M. (2018). "It's a long-term process": description of daily family life when a child has a feeding disorder. *J Pediatr Health Care*, 32(4), 340-347.
- Fadda, G. M. & Cury, V. E. (2019). The experience of parents in the relationship with their child diagnosed with autism. *Psic. Teor. e Pesq.*, 35(spe).
- Fernandes, A. D. S. A.; Speranza, M.; Mazak, M. S. R.; Gasparini, D. A. & Cid, M. F. B. (2021). Everyday challenges and caring possibilities for children and adolescents with Autistic Spectrum Disorder (ASD) in the face of COVID-19. *Reflection Article/Essay. Cad. Bras. Ter. Ocup.*, 29.
- Ferreira, M. & Smeha, L. N. (2018). The experience of being a mother of a child with autism in the single-parenthood context. *Psicol. Rev.*, 24(2), 462-481.
- Gallo, A.; Wertz, C.; Kairis, S. & Blavier, A. (2019). Exploration of relationship between parental distress, family functioning and post-traumatic symptoms in children. *European Journal of Trauma and Dissociation*, 3, 125-133.
- Lima, R. C. & Couto, M. C. V. (2020). Perceptions on autism and experiences of overload in everyday care: a study with relatives of CAPSi from the Metropolitan Region of Rio de Janeiro. *Brazilian Journal of Mental Health*, 12(31), 217-244.
- Lu, C.; Yuan, L.; Lin, W.; Zhou, Y. & Pan, S. (2017). Depression and resilience mediates the effect of family function on quality of life of the elderly. *Arch Gerontol Geriatr.*, 71, 34-42.
- Machado, G. D. S. (2019). The importance of routine for autistic children in basic education. *GepesVida Magazine*, 9(1), 100-114.
- Mapelli, L. D.; Barbieri, M. C.; Castro, G. V. D. Z. B.; Bonelli, M. A.; Wernet, M. & Dupas, G. (2018). Child with autistic spectrum disorder: care from the family. *Esc Anna Nery*, 22(4), e20180116.

- Menezes Neto, J. B. de; Silva, E. de S. M. e; Figueira, G. M.; Souza, J. C. The stigma of mental illness among students and health professionals. *Research, Society and Development*, [S. l.], v. 10, n. 3, p. e8310312899, 2021. DOI: 10.33448/rsd-v10i3.12899. Disponível em: <https://rsdjournal.org/index.php/rsd/article/view/12899>. Acesso em: 15 sep. 2022.
- Mira, A.; Berengher, C.; Baixauli, I.; Roselló, B. & Miranda, A. (2019). Family context of children with autism: implications for social and emotional development. *Medicine*, 79(Supl.I), 22-26.
- Mitchell, A. E.; Whittingham, K.; Steindl, S. & Kirby, J. (2018). Feasibility and acceptability of a brief online self-compassion intervention for mothers of infants. *Arch Womens Ment Health*, 21(5), 553–561.
- Ortega, F. (2009). Disability, autism and neurodiversity. *Ciênc. Saúde Coletiva*, 14(1), 67-77.
- Pereira, A. I. L.; Fernandes, O. M. & Relva, I. C. (2018). Psychopathological symptomatology and social support in parents of children with autism spectrum disorder. *Análise Psicológica*, 36(3), 327-340.
- Plumb, J. C. (2011). The impact of social support and family resilience on parental stress in families with a child diagnosed with an Autism Spectrum Disorder [dissertation]. University of Pennsylvania.
- Portes, J. R. M. & Viera, M. L. (2020). Coparenting in the family context of children with autism spectrum disorder. *Psicol. Estud.*, 25.
- Pratt, K. J. & Skelton, J. A. (2018). Family functioning and childhood obesity treatment: A Family Systems Theory-informed approach. *Acad Pediatr.*, 18(6), 620–627.
- Predescu, E. & Şipoş, R. (2017). Family quality of life in autism spectrum disorders (ASD). In: Fitzgerald, M. & Yip, J., editors. *AUTISM paradigms, recent research and clinical applications*. InTech, Chapter 7, 87-111.
- Reddy, G.; Fewster, D. L. & Gurayah, T. (2019). Parent's voices: experiences and coping as a parent of a child with autism spectrum disorder. *S. Afr. J. Occup. Ther.*, 49(1), 43-50.
- Ribeiro, S. H.; Paula, C. S.; Bordini, D.; Mari, J. J. & Caetano, S. C. (2017). Barriers to early identification of autism. *Braz J Psychiatry*, 39(4), 352-354.
- Segeren, L. & Françoço, M. F. C. (2014). The living experiences of mothers of autistic youngsters. *Psicol. Estud.*, 19(1), 39–46.
- Smeha, L. N. & Cezar, P. K. (2011). The living of maternity with autistic children mothers. *Psicol. Estud.*, 16(1), 43-50.
- Starr, E. M. & Foy, J. B. (2012). In parents' voices: the education of children with autism spectrum disorders'. *Remedial Spec Educ.*, 33(4), 207-216.
- World Health Organization (WHO). (2013). Comprehensive and coordinated efforts for the management of autism spectrum disorder. [https://apps.who.int/gb/ebwha/pdf\\_files/eb133/b133\\_4-en.pdf](https://apps.who.int/gb/ebwha/pdf_files/eb133/b133_4-en.pdf).