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SOCIAL PAIN AND PARENTAL PERCEPTION OF PARENTS OF CHILDREN WITH ASD IN THE SCHOOL CONTEXT

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ABSTRACT

This study described an integrative review of the literature on the impact of the diagnosis of Autism Spectrum Disorder in the family context correlated with family social pain after diagnosis and the anguish of the school inclusion process. Presenting as a general objective, to verify the existence of necessary and sufficient support for children with ASD, beyond the family context, and with the specific objective of providing contact with peers of the same age group. The methodology is based on an integrative literature review, between the periods of 2019 and 2024 in the Scielo, LILACS, PePsic and PsychInfo databases, with the Boolean descriptors "perception of autistic parents", "parents of autistic children", "school inclusion of autistic children" and "schooling of autistic children". The results were presented in three topics of discussion: the first topic describes the impact of the diagnosis of Autism Spectrum Disorder, the second topic presents the processes of "social pain" and narrowing of social relationships in the face of the behavioral actions of children and the third topic presents the importance of the process of inclusion of children with ASD in the school environment. The article highlights the need for further research on the subject due to the difficulty of finding more information in Brazilian contexts.

Keywords: Autism Spectrum Disorder. Parenting. Social Pain and School Inclusion.

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INTRODUCTION

Autism Spectrum Disorder – ASD is a multifactorial neurodevelopmental disorder that presents significant changes in social interactions, social reciprocity, restricted and/or repetitive patterns; impairment in language and unusual interests. (APAS, 2023).

Its diagnosis must be presented from early childhood for significant interventions in the child's development process, however, the presence of the diagnosis causes relevant impacts on the family environment due to several issues, among which the process of mourning for the idealization of the "perfect" child in terms of social representations stands out (Santos, et al 2019).

The diagnosis of ASD has a great impact on the family context, and the need for support for parents at this time is very important, so that both they and their children develop in the best way. (Rodrigues, et al 2021).

Unfortunately, the family support process often does not include everyone, we have a philanthropic institution mirrored around the world since 1983 with the name of Association of Friends of the Autistic – AMA, however many families are unaware or are not part of this association.

According to the research carried out by Aguiar and Pondé (2020), in the search for coping strategies, parents made it clear that they need to receive care to take care of their children and this is an important aspect to be remembered not only at the time of diagnosis, but throughout the process of caring for individuals with ASD.

After the diagnosis, families go through several phases, among them the search for denial, "cure", acceptance of relatives, difficulty in maintaining treatment and especially current beliefs and beliefs about future perspectives due to diversified behaviors of the "standard". For Kruger, 2018, the beliefs acquired and elaborated from personal experiences during social interaction have repercussions in different ways on other cognitive processes, motivation, affectivity and human relationships.

In view of the entire process of diagnosis and treatment, the school environment is another important reference for parents of children with ASD. After the tireless search for treatments for the child, there is also the need to integrate him into society, and this could be favored by the child's entry into school. (Smeha and Cezar, 2011).

However, sometimes the family, due to lack of information, or by identification of peers within the family context, verbalize the normality of the situation, end up not noticing some developmental delays, or thinking that this delay is not significantly accentuated, and it is at school that this information is passed on to the beginning of an investigation process.

At times, it is at school that teachers helped in the initial identification of behavioral changes, which motivated families to seek help, enabling early diagnosis, as well as positive implications for the prognosis of the disorder and for the lives of children and their families. The articulation between educational and health institutions with other care devices for this population is important and necessary. (BONFIN, et al 2019).

The family needs to be linked to the school, so that it can present positive results in the child's development, on the other hand, the family also needs the support of the child's intervention team so that it can be aware of its potentialities and limitations, working together with everyone for a better development.

METHOD

The present research is an integrative review of the literature that aimed to present the importance of the social interaction of children with ASD in the school context. With the general objective of verifying the existence of necessary and sufficient support for children with ASD, beyond the family context, and with the specific objective of providing interaction with peers of similar age groups. The present studies were published in Brazil between 2019 and 2024, with the aim of considering the intercultural process. The data collection was carried out in the Scielo, LILACS, PePsic and PsychInfo databases with the descriptors "perception of autistic parents", "parents of autistic children", "school inclusion of autistic children" and "schooling of autistic children" and Boolean operators "AND". A total of 250 articles were found with the descriptors, to perform an analysis by title and later the complete reading of the articles. Duplicate articles, articles outside our cultural reality, theses, dissertations, and articles that are not free to use were excluded from the search.

RESULTS AND DISCUSSIONS

PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

The process of conceiving a child is always something highly anticipated in many families, especially when there is planning for the coming of that long-awaited being. However, the arrival of a child with ASD and its implications for the marital subsystem bring with it both stressors and risk factors to the couple's health, such as: care overload, conflicts due to behaviors characteristic of the disorder, isolation, lack of social support and time alone with the partner and even, the socioeconomic situation; and protective factors, associated with communication and dialogue, union, division of tasks, partner support and support networks. (MACHADO, et al, 2022).

It is therefore important that the diagnosis occurs as a process and not in a punctual way and that the information about ASD is offered in a clear way, in simple and concrete language, allowing parents a greater assimilation of the content received. Clarification about ASD helps families to better understand the disorder and to organize themselves in the face of the difficulties faced in daily life. (FEITOSA and SOLOMON, 2023).

Due to the whole process of family reformulation, the fact that the initial coexistence of the child with ASD requires greater dedication to the children, sometimes providing an emotional and physical overload of the other members, especially the mother. (FONSECA, et al, 2019).

Studies show that the challenges encountered in the experiences of women whose child is diagnosed with ASD generate a series of changes in their lives. (FARO, et al, 2019).

Mothers who welcome the difference of their children, despite their expectations of broken motherhood, subjectively build new relationships with them to make this experience possible. Caring for a child with autism is a complex task permeated with contradictions, but it is also dealing with them in their daily lives that allows the construction of the subjective place of "mothers of autistic people". Dealing with it on a daily basis means following the "atypical" development of your children, learning from them that the waiting time for "developmental milestones" is different, that the ways of communicating are diverse. (FREITAS and GAUDENZI, 2022)

In advance, the training of health services and professionals to meet the demands of ASD, investigating parental beliefs and the factors that relate to them, can promote a higher quality of life for families and more effective interventions. In this scenario, it is possible to help families to signify the child's diagnosis and reformulate their beliefs and expectations about the child and their role as parents. (FEITOSA and SOLOMON, 2023).

Bearing in mind that such families also present positive aspects after the discovery of the disorder, uniting and restructuring to adapt to the needs of the child with autism. (RODRIGUES, et al 2020).

Recent studies address a better adaptation of parents to the diagnosis of children with ASD, through the presence of positive expectations related to the child and the belief that children can have a good quality of life, develop academic skills and greater autonomy. (FEITOSA AND SALOMÃO, 2023).

SOCIAL PAIN OF PARENTS WITH CHILDREN WITH ASD

Human beings are beings who always live in a social context. For Canaipa (2014), there is a long period of dependence on parents, justifying the need and importance of biological mechanisms in order to maintain social connections.

Based on the assumption of the importance of social relations, Eisenberger, Lieberman and Williams (2003) propose the existence of "social pain", a concept that refers to the suffering that results from the loss or threat to the integrity of significant social relations.

Social relationships are altered when family demands are priorities. The daily life of families with children with ASD is extremely tiring, especially for mothers who bring care for children with ASD as a priority. Mothers dedicate themselves fully to this care, traveling long trajectories in search of diagnoses and treatments, wandering through health services, resulting in a lack of time for self-care, professional, social and leisure activities. As a consequence of this full-time dedication, studies point to the emotional overload with facing this phase. (PINTO and CONSTANTINIDIS, 2020).

Faced with the context of divergent behaviors in each child, such as motor stereotypies, echolalia and sometimes total absence of orality, the family is in constant anguish and despair. ASD causes important influences on family and social relationships, given that soon after the diagnosis there are difficulties in dealing with the symptoms and the insufficiency of health, education and leisure services. (FONSECA, et al, 2019).

Dealing with the singularities of children with ASD on a daily basis is also experiencing a daily life that is often presented as violent. Both children and their families are inserted in an environment that is not prepared for their ways of being in life and unfortunately they reap the effects of stigma and prejudice arising from their atypical performances. (FREITAS and GAUDENZI, 2022)

The lack of acceptance of the differences of children with ASD, the prying eyes and the most diverse prejudiced situations tend to cause families to avoid social life. Studies by Zanatta, et al (2014), pointed out in their exploratory research with mothers of children with ASD report that in an attempt to spare their children from curious looks, prejudices and lack of understanding in the face of a divergent behavior "crisis", they prefer to be restricted to their homes with the absence of leisure. This action is highlighted as an important point of identification among mothers and mobilizes them to get together and help other mothers. (FREITAS and GAUDENZI, 2022)

Social perspectives are evident in situations that are out of context experienced by each individual. In the presence of all the complexity and the moment of fragility, the relationship between these fathers and mothers and their children diagnosed with ASD was initially characterized by feelings of exhaustion, loneliness, helplessness and vulnerability. (FADDA and CURY, 2019).

Due to the process of representation of social pain, it is perceived as essential to promote reflections and spread information about autism in society in order to make the disorder and its particularities known in order to then stimulate the understanding of the community in order to combat prejudice, which affects people with ASD and their families. (DIAS, et al, 2021)

CHILDREN WITH ASD IN SCHOOLS, POSSIBILITIES AND CHALLENGES

The educational process is one of the most important avenues for the relations of formal learning and social learning. However, although school inclusion in Brazil has legal support with national policies for inclusion, academic experiences are still distressing factors for many families of children with ASD.

The school is practically the only place to provide continuous and daily social support to children with ASD, it is in this space that children will live with peers at similar ages and develop. Many parents look for a school in which they perceive a commitment to the development of their child and respect from the staff. (FADDA and CURY, 2019).

The importance that the family has in school participation is related to the contribution of the formation of the educational development of its children. The family needs to show interest and value what the student produces. It is possible to notice that in the teacher's day-to-day work, when there is support, attention directed to the needs of each child, learning happens in a more assertive way. A good relationship between the family and the school must be present in any educational work that has the student as its main target. (LOPES and TELASKA, 2022).

The process of inclusion is not only beneficial for the people who are being included, but for everyone around them. For Lemos, et al (2020), the benefits of school inclusion are understood both in terms of the atypical child and other children, who develop skills related to tolerance, respect and empathy through school experiences.

However, in addition to gaps in the knowledge of family members and professionals about the ways to include children with ASD in school, requiring greater professional training for the necessary support to the family, it is a guarantee of the learning and well-being of these children. Therefore, it is necessary to dialogue, the search for adequate training and possible curricular reforms in undergraduate courses, envisioning the gradual improvement and awareness of society, especially of professionals, in order to provide discussions, boost debates and facilitate the relationship between the school and family. (VASCONSELLOS, et al, 2021).

The importance of research on the action of teachers with students with ASD in the inclusion process is emphasized. For Oliveira (2021), research carried out in the municipality of São Paulo pointed out the need for theoretical knowledge on the part of educators about the characteristics of ASD; lack of information on the improvement of pedagogical practices to adapt them to the student; and lack of specific activities for each subject so that the student with ASD has greater absorption of content.

The lack of information about the etiology of Autism Spectrum Disorder and its daily attributes throughout the environment lead the teacher to doubts about what to do and how to act. In view of this, it was found that there are impasses in the school routine, due to the lack of adequate training of teachers and other professionals, causing a feeling of impotence or lack of understanding regarding the behavioral characteristics of these children, who are sometimes stereotyped only as to their negative aspects, which hinders child learning and development. (VASCONSELLOS, et al, 2021).

However, it is understood that the difficulties imposed by ASD are not necessarily configured as limitations that completely prevent interactions. Although it is not possible to establish correlations between behaviors and contexts, it is important to analyze social interactions in these scenarios, verifying the participation of children with ASD and their peers, considering the context, the type of activity, the mediation of teachers and mutual influences based on the concept of bidirectionality. (LEMOS, et al, 2020).

In the Brazilian scenario, the biggest difficulty for the inclusion of children with ASD, according to teachers, is the lack of specialized training. Although the reception of these students in the classroom is less distressing for the teacher when the child does not have learning problems and/or aggressive behaviors, according to teachers, the biggest problem of inclusion does not concern the impossibility of keeping the student with ASD in regular school, but the need for teachers to be prepared to receive them. (Ponce and Abrão, 2019)

Even in the face of so many variables, the teacher starts to ally himself with the students' learning, thus facilitating the engagement of the student with ASD in the class routine and in their integral development. Weizenmann, et al (2020), presented in their research that the first feelings that prevailed in teachers, after receiving a student with ASD in their class, was fear and insecurity. However, after the student's adaptation period and the construction of bonds, this feeling was gradually replaced by positive affections and pedagogical practice built in an individualized and singular way.

It is essential that the educational practice is based on the student's uniqueness, so that the teacher respects his difficulties without, however, being tied to them, because, in the context of inclusion, the teacher must have a look at potentials to be developed. Their posture should aim at the emancipation of the subject and their desire, which is only possible from a rejection of pedagogical idealizations and a willingness to find something different from what the metaphors created to refer to ASD preach, because based on this principle the student will be denied the possibility of building bonds, expression of feelings and apprehension of reality. (PONCE and ABRÃO, 2019).

After the diagnosis process, some family members receive the suggestion of the health professional to place the child in school environments, so that this child can expand his repertoire beyond family life and perceive his surroundings, helping in his development process. Social attitudes have cognitive, affective and behavioral components, which suggests multidetermination in their formation, as each individual has his or her perception of the environment. (BENITEZ, et al, 2021).

As challenging as the entry of a student with ASD into the school environment is, regardless of their limitations, there is full recognition that inclusion is a favorable path that enables the reduction of prejudice and practices of social exclusion; Despite this, it is evident that the recognition of the importance of inclusion, by itself, is not capable of breaking with old paradigms that tend to promote resistance in the face of this new reality. (PONCE and ABRÃO, 2019).

FINAL CONSIDERATIONS

Autism spectrum disorder is a neurodevelopmental disorder with multifactorial impairment that affects processes of social interaction, language and diversified behaviors. (APAS, 2023).

Because it is a disorder with significant impairments in the individual's development, the social representation is seen immediately by the absence of information or by extremely intense behaviors, such as not greeting when an acquaintance interacts with the child, crises due to excessive sensory stimuli such as light and/or sounds, causing families to be alert to this information and start seeking help.

The evaluation and diagnosis process brings anguish and frustration to many family members in the face of various dreams and expectations, the demystification of the ideal child, the need for a grieving process and the search for specialized treatment.

The diagnosis seems to be a guide for the family member, who, until then, may feel adrift with their experiences and alienated from their actions. The psychopathological diagnosis is a place that the experiences of family members come to occupy, and can be referred to with a name. It leaves the category of unnamable to the concreteness of a code to be shared, giving a guarantee of illness to what they experience in the relationship with the child. Thus, the diagnosis is not only a need for professionals, who often avoid the task of talking about the topic with the family, but also for family members. (CONSTANTINIDIS et al, 2018)

However, the presence of the diagnosis brings a process of vast fatigue and fatigue due to issues of conciliation of work, therapies, school and family. Many families that cannot count on a support network end up overloading themselves or dividing the tasks into parts that are not equal to everyone, such as the father responsible for the financial and the mother for promoting the other attributions related to the child and the home. Vilanova, et al (2022) in their study pointed out maternal burden in the care of children with ASD.

Faced with the overload and limitations of the children, families no longer attend the social relationships they previously attended due to several factors that may be correlated with shame due to the child's divergent behaviors, concern with what others will say in a moment of crisis, even due to the child's hypersensitivity to sensory stimuli. The absence of a support network and social support for the family, especially the caregiver, can generate complex conditions of social isolation, overload, stress and difficulties in observing positive child aspects. (FEIOTOSA and SOLOMON, 2023).

In this context, many families end up isolating and keeping their children isolated, so that they are afraid to place them in an academic environment so that the child can develop with peers of similar age groups.

However, the school, after family references, is the second gateway between the child and their social contexts, even with limitations, children learn by imitating peers with similar ages and the school is the gateway to this interaction.

Even with the inclusion laws and the process of specialized educational care, some teachers still verbalize the absence of information and materials for children with ASD. However, research points out that the family together with the school helps in the development process of these children. The family, as the first instance of social order, knows how the child develops and when starting school life, brings with it the knowledge obtained in his family and social life, at school the ways to develop his skills will be shown. (SILVA and ENGELBRECHT, 2019).

In view of the context of the aforementioned integrative literature review, this research presented important information so that parents can allow their children to enter the school environment, continuously and gradually monitoring their development. The research presented the need for better teacher training for better care and training of children with ASD, explaining the need for further research on the subject.

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