ABSTRACT: This study is guided by the following research question: How does the family influence the learning of people with Autism Spectrum Disorder (ASD)? Was carried out an integrative literature review in the Scielo database (Scientific Electronic Library Online), through of combination of the following descriptors: autism; family; and learning. We’ve obtained 21 articles, between empirical (13) and bibliographic researches (8), which established the following relation with the research question: direct relation; indirect relation; relation while affirmative assumption. The results are in accordance that family participation in therapeutic and pedagogical interventions is important. However, there is a need to overcome a biomedical conception, in order to include systemic and inclusive conceptions, which conceived the roles of the family as protagonists in complex realities.

RESUMEN: Este estudio se guía por la siguiente pregunta de investigación: ¿Cómo influye la familia en el aprendizaje de las personas con trastorno del espectro autista (TEA)? Se realizó una revisión de literatura integradora en la base de datos Scielo (Scientific Electronic Library Online), mediante la combinación de los descriptores: autismo; familia; y aprendizaje. Se obtuvieron 21 artículos, incluyendo investigaciones empíricas (13) y bibliográficas (8), que establecieron la siguiente relación con la pregunta de investigación: relación directa; relación indirecta; relación de suposición afirmativa. Los resultados indican el consenso sobre la importación de la participación de la familia en intervenciones terapéuticas y pedagógicas. Sin embargo, se percibe una necesidad de superar una concepción unicamente biomédica, con el objetivo de considerar las concepciones sistémicas e inclusivas, que conciben la familia como protagonistas en realidades complejas.


Introduction

Currently, autism is not considered a disease, as it does not have a morbid consumptive character that can lead to some type of physical degeneration or even eventual death. This perspective is recognized as the paradigm of neurodiversity, which according to Wuo (2019, p. 213) “sees autism as a difference that characterizes the subject's uniqueness and not a disease”.

This way of looking at autism avoids associating it with an idea of ill health, although, often, the autistic person needs rehabilitation work that leads to a better social life and adaptation to academic activities, which leads health professionals still call their autism-related interventions 'treatment'.

It is also noteworthy that the concept of disease is related to broad socio-historical aspects, linked to the power of medicalization of medicine.

For the purposes of contemporary classification, from 2013, with the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders - DSM-5, Autistic Spectrum Disorder (ASD), started to include autistic disorder (autism), Asperger's, childhood disintegrative disorder, Rett's disorder and global developmental disorder without further specification of the DSM-IV, being characterized by deficits in two central domains: 1) deficits in social communication and social interaction and 2) repetitive and restrictive patterns of behavior, interests and activities (AMERICAN PSYCHIATRIC ASSOCIATION, 2014).

The ASD is also not considered a disability, as its characterization does not refer to any deficit in cognitive or intellectual capacity, although there are cases that present comorbidities.
However, for legal purposes in Brazil, from Law no. 12,764 of 2012, the person with ASD now has the same rights as the person with a disability. Implying, for example, the requirement that regular schools receive the autistic child.

According to Baña Castro (2015), it was due to the predominance of the clinical-medical model that until recently the role of family educator did not have its due importance.

A study by Guedes and Tada (2015), a review of the scientific literature on autism in the fields of Psychology and Education, identified the scenario of scientific production from publications in Brazilian journals between 2007 and 2012. One of the categories analyzed was 'Autism and family relationships', which brought together 18 articles that addressed topics related to: caregiver quality of life (9); impact on family dynamics (5); mother-child relationship (4).

However, none of them specifically addressed the family influence on the development and learning of the autistic person, even though they consider the family “an essential support for the development of the person with autism with multiprofessional therapies” (GUEDES; TADA, 2015, p. 306).

Thus, we contribute to the theme through a literature review on the influence of the family on the learning and development of people with ASD.

**Methodology**

This review was updated in January 2020, in the database of Scielo (Scientific Electronic Library Online), an electronic library that provides articles from Brazilian scientific journals and 13 other countries.

The literature review was carried out using the Integrative approach, because, being broader, it allows the inclusion of different types of research to understand the analyzed phenomenon.

In summary, the following steps were used to carry out the integrative review: elaboration of the theme and guiding question; search for sampling in the literature, with the establishment of inclusion and exclusion criteria; organization and selection of studies; critical analysis; discussion of results; presentation of the review.

Having as theme the influence of the family in the learning and development of autistic children, the following guiding question was used: How does the family influence the learning of people with ASD?
In this research, learning was understood in a generic way, considering all the acquisition of new behaviors, skills and knowledge that are part of human development, such as communication and social interaction.

The inclusion criterion in this study was: research articles from various methodological procedures, and areas of study, which are positioned in relation to the family's influence on the learning of autistic people.

Were excluded studies: which do not deal with learning; that do not deal with the family; that address the impact of an autistic child on the family without reflecting on learning and development; that in the analysis of the data do not specify those referring to families with autistic people.

The combinations of descriptors used were: ‘autism’, ‘family’ and ‘learning’. With the combination of the three descriptors, 5 articles were reached, which directly or indirectly address the family's relation with the learning of autistic people. Subsequently, only the descriptors ‘autism’ and ‘family’ were used, and 59 articles, of which 18 were selected. Finally, the descriptors ‘autism’ and ‘learning’ were combined, with 40 articles, of which 8 were selected.

Considering the recurring articles in the descriptor combinations, 21 articles, published between 2003 and 2019, were selected and analyzed. A large part (10) published in the last three years (2017, 2018 and 2019), indicating a recent increase in research that addresses in some way the family influence in the learning of autistic people. Regarding the origin of the publication: 17 are from Brazilian journals; 2 from Uruguay; 1 from Costa Rica; and 1 from Portugal.

The selected material was classified for analysis regarding the type of research: empirical (13), bibliographic (4), bibliographic literature review (4); and as for its relation to the guiding question: direct relation (9), indirect relation (8), or relation as an affirmative assumption (4).

**Critical analysis**

Of the 21 selected articles, 4 presented the influence of the family on the learning of the autistic person as an assumption, that is, not as something to be answered by the investigation, but as a priori knowledge that justified the realization of the same or its propositions.
Merlleti (2018) highlights the importance of caring for those who care for the child, stating that it is the parents who provide continuity of treatment.

Reis, Pereira and Almeida (2016) emphasize that the family must be trained and co-responsible to support the development of their children and understand the importance of effective and constant collaboration between family and professionals so that the results of the interventions are achieved.

The influence of the family is not always presented as a positive assumption. Thus, De Tilio (2017) in a study conducted in the state of Minas Gerais (Brazil) with the sister caregiver of an autistic adult, presents the assumption that when family members/caregivers do not recognize the possibilities of development (biological and psychological, including sexuality), in order to infantilize, deny or reject, it makes it difficult for autistic people to learn to deal with their own bodies and their sexuality.

Coelho, Lemma and Lopes-Herrera (2008, p. 80) considers family support to be such an important factor that, in a case study conducted in the interior of São Paulo (Brazil), they question “to what extent the maintenance of autistic characteristics and the behaviors presented by the child are being determined by the sensory deprivation he/she suffers, or even by the severity of the autistic condition in question”6.

Affirming the influence of the family implies recognizing the potential that the autistic person has, even in relation to those skills that are developed with greater difficulty, such as the case of social interaction.

The literature review carried out by Camargo and Bosa (2009) aimed to critically revisit the literature regarding social competence in studies in the area of autism and school inclusion. Although the authors considered, at the time, that there were few studies on the subject and with methodological limitations, they point to the identification of social competence in autistic children.

Among the researches reported, they present the study by Serra (2004 apud CAMARGO; BOSA, 2009, p. 70) that when carrying out the study with an autistic boy with seven years of age, about school inclusion, found “[... ] positive effects of inclusion in the family, due to the greater investment in the child's learning and an increase in credibility in the child's potential”7.

6 “até que ponto a manutenção das características autistas e os comportamentos apresentados pela criança estão sendo determinados pela privação sensorial que esta sofre, ou mesmo pela severidade do quadro autístico em questão”

7 “[...] efeitos positivos da inclusão, na família, em função do maior investimento desta na aprendizagem da criança e um aumento na credibilidade nas potencialidades do filho”
Among the bibliographic research, the researcher's communication, from the Spanish University of Coruña, Baña Castro (2015), published in the magazine of the Catholic University of Uruguay, stands out. For the author, the educational support of the family is essential, since it facilitates the support and development opportunities of the person with autism beyond their changes and difficulties.

Baña Castro (2015) supports a global and systemic position, aiming to overcome the biomedical model, that is, not focusing on the pathological and the deficit, but on an educational cut. Thus, the needs and demands of the individual and families are considered, and the family is no longer a mere passive extension of the professionals' work.

The literature review carried out by Wuo (2019) on theses and dissertations in the South and Southeast regions of Brazil, between 2008 and 2016, demonstrated that there is still a predominance of medical areas and, consequently, linked to the notion of deficit and psychological and social.

It is recognized, however, that since 2008, with the National Policy on Special Education from the perspective of Inclusive Education, there has been an increase in educational research on autism, as an alternative to exclusively medical models of looking at the difference. This trend contributed to the development of a systemic view and has placed the family as an important factor in the themes highlighted by Wuo (2019) as: intervention with family members of people with ASD; school-family relations within the scope of school inclusion.

The emphasis on a systemic perspective, as defended by Baña Castro (2015), is closer to an inclusive perspective, since it defends that the social media, and the people, in which the individual is inserted can be transformed so that there is really genuine inclusion.

Lampreia's study (2007), on the other hand, analyzes some early intervention programs from a developmental perspective, which seeks to understand the deviations in the child's development from the typical development. In other words, it is an approach close to the biomedical model because it focuses on the deficit.

The identification of autism from the age of 18 months enables early intervention, which in the developmental perspective has a pragmatic and social characteristic, in which, assuming cerebral plasticity, it seeks to “establish the path of development of the precursors of language that it was not possible to follow, regardless of the etiology”8 (LAMPREIA, 2007, p. 106).

---

8 “estabelecer o caminho de desenvolvimento dos precursores da linguagem que não foi possível percorrer, independentemente da etiologia”
Parents becoming co-therapists is a requirement for the success of the programs, since most of them occur in the family environment and daily.

On the other hand, it is concluded that “there are so many variables involved that greater experimental control is practically impossible”\(^9\), so that “it cannot be said that the behavioral changes observed are due to the intervention and not to the child’s development”\(^10\) (LAMPREIA, 2007, p. 113).

Still on early intervention, Caldeira da Silva \textit{et al.} (2003) describe a clinical program, developed in Portugal, based on the DIR model (Developmental, Individual-difference, Relationship-based Model), also present in the study by Lampreia (2007).

According to Caldeira da Silva \textit{et al.} (2003, p. 32) "is a model of intensive and global intervention, which associates the Floor-time approach with the involvement and participation of the family, with different therapeutic specialties and the articulation and integration in the educational structures"\(^11\).

Caldeira da Silva \textit{et al.} (2003, p. 37) concluded in their study that “both for the clinic and for the adhesion of families and technicians, that this is a useful and sufficiently effective model to be recommended for its application and dissemination”\(^12\).

We note, however, that as with the articles reviewed by Lampreia (2007), the article by Caldeira da Silva \textit{et al.} (2003) presents a description of the program without, however, mentioning experimental data regarding its effectiveness.

In a literature review on psychoeducational interventions, Bosa (2006) identified a growing recognition about the importance of involving both the needs of the autistic child and the family.

For Bosa (2006) the results of intervention research in cases of autism should be interpreted with caution, as there are a large number of studies that are not well controlled methodologically. Furthermore, the author assesses that “apparently, there is no single approach that is totally effective for all children, in all different stages of life”\(^13\) (BOSA, 2006, p. 52).

---

\(^9\) “são tantas as variáveis envolvidas que se torna praticamente inviável um maior controle experimental”

\(^10\) “não se pode afirmar que as mudanças comportamentais observadas se devem à intervenção e não ao próprio desenvolvimento da criança”

\(^11\) “é um modelo de intervenção intensiva e global, que associa a abordagem Floor-time com o envolvimento e participação da família, com diferentes especialidades terapêuticas e a articulação e integração nas estruturas educacionais”

\(^12\) “tanto pela clínica como pela adesão das famílias e dos técnicos, que este é um modelo útil e suficientemente eficaz para ser recomendada a sua aplicação e divulgação”

\(^13\) “aparentemente, não existe uma única abordagem que seja totalmente eficaz para todas as crianças, em todas as diferentes etapas da vida”
Lyra et al. (2017) performed a literature review in the database of systematic reviews Cochrane\textsuperscript{14} on interventions for ASD. Among the 17 reviews consulted, none presented strong evidence. Specifically, in relation to early interventions mediated by parents, the evidence was considered weak. Aspects related to language and communication, the child's initiation into interaction with parents, adaptive behavior, brought inconclusive and inconsistent results.

There was, however, evidence of a positive and statically significant change in the patterns of interaction between parents and the child, evidence suggestive of improved understanding of children's language and a reduction in the severity of the characteristics of childhood autism. (LYRA et al., 2017).

The great heterogeneity of profiles of children and families creates difficulties in the appropriation and control of variables in complex and systemic contexts. In this sense, Lampreia (2007) suggests that in addition to engaging parents in programs, family stressors and their impact on the child should be considered.

Two selected empirical studies help to discuss the complexity in relation to family dynamics: the study by Mapelli et al. (2018) and Sifuentes and Bosa (2010).

In the study by Sifuentes and Bosa (2010) 5 couples from Porto Alegre participated, with children with a supposed diagnosis of autism and aged between 4 and 7 years. Four dimensions of the concept of coparenting were analyzed: the division of labor related to child care, which comprises parenting tasks such as feeding, organizing hygiene habits, transportation, helping with school tasks and accompanying the child in recreational activities; moments of solidarity and support; dissonance and antagonism; and spontaneous situations of the parents towards the child. The results show that there is no equal sharing of responsibilities between father and mother, although there are some divisions that follow very personal criteria, such as affinity, or even lack of time.

It was also found that there is an overload of tasks on the part of the mother and that one of the biggest sources of conflict between father and mother are disagreements regarding educational practices. (SIFUENTES; BOSA, 2010).

In the study by Mapelli et al. (2018) there were 22 participants (father, mother, siblings) from 15 families with children up to 12 years old, living in the interior of São Paulo. The results affirm that the process experienced by the family is dynamic, and that in terms of its influence on learning, the study revealed the commitment, especially of the maternal figure, “to provide

the best care, including in terms of stimulating the development of the child's potential" (MAPELLI et al., 2018, p. 6).

It is also suggested that the health team should understand the family, its structure and functioning, that is, understand how this family's organization occurs, its relationships and resilience (MAPELLI, 2018).

About studies with families that have a member with ASD in adulthood, two studies were selected, one of them, mentioned above, De Tilio (2017), made the study only with a family caregiver. The study by Rosa, Matsukura and Squassoni (2019) conducted the application of electronic questionnaires to 67 family members, in 14 Brazilian states, linked to groups or institutions that work with autistic adults.

Despite not directly researching the influence of family members on learning in the autistic person, Rosa, Matsukura and Squassoni (2019, p. 313) suggest that family participation was essential during the history of the subjects studied, especially to deal with the challenges of the process inclusion; in addition to reinforcing the importance of sharing between school and family regarding the responsibility to educate by viewing “the real potentialities and possibilities” of children with ASD.

Regarding the research source, the study by Bialer (2017) stands out for using autobiography. The author analyzes the autobiographical records of an American family, published by her mother, whose daughter had severe autism. It focuses on the first 15 years of life of the biographer, portraying the evolution of the symptomatic picture.

Bialer (2017, p. 1034) emphasizes the importance of the family, more specifically the intervention of the mother (Clara) in the development and learning of the daughter (Jessy). Although Jessy appeared to be in balance in her world, isolated and “disconnected from everything and everyone”, the mother understood that this balance denied the possibility of growth.

Bialer (2017, p. 1028) highlights the mother's posture:

Analyzes all the situations in which Jessy could get out of isolation, trying to recreate the conditions that made it possible to get out of autistic withdrawal. Concomitantly, she registered sensitive areas in which Jessy should not be pressured at risk of reactive withdrawal, emphasizing the importance of respecting her subjective time."

---

15 “em prover o melhor cuidado, inclusive em termos de estímulo ao desenvolvimento das potencialidades da criança”

16 Analisa todas as situações nas quais Jessy podia sair do isolamento, procurando recrivar as condições que lhe viabilizavam sair do retraimento autístico. Concomitantemente, registrou áreas sensíveis nas quais não se devia pressioná-la sob risco de um retraimento reativo, realçando a importância do respeito ao seu tempo subjetivo.
Six empirical researches directly related to the guiding question of this literature review were identified: Menotti, Domeniconi and Benitez (2019); Balestro and Fernandes (2019); Cossio, Pereira and Rodríguez (2017); Rodrigues-Roblero (2015); Benitez and Domeniconi (2014); Fernandes et al., (2011).

The study by Menotti, Domeniconi and Benitez (2019) evaluated the effectiveness of an instructional package for the teaching of reading fifteen dissyllable words (isolated) for children with ASD, based on the reading model as a network of relations. Three children and their parents participated, who were involved through the use of games, which favored the interaction between the dyad and created conditions for their more effective participation in the children's school process. The results indicate that the procedure favored the increase in the reading repertoire of children with ASD.

With a similar direction, the study by Benitez and Domeniconi (2014) operationalized and evaluated a reading and writing teaching qualification for regular school students with intellectual disabilities and autists. This included ‘regular classroom teachers’, ‘special education teachers’ and parents, in order to envision shared teaching.

The results indicate that the capacitation contributed “in the operationalization of inclusive teaching strategies, in order to serve the apprentices with different characteristics, different learning rhythms and differentiated potential”17 (BENITEZ; DOMENICONI, 2014, p. 384).

Just as Menotti, Domeniconi and Benitez (2019), Benitez and Domeniconi (2014, p. 381) suggest that the "entanglement" between family and teachers, as educational agents, should be understood as a "promising teaching strategy from an inclusive perspective"18.

The study by Cossio, Pereira and Rodríguez (2017) aimed to understand the benefits of supporting early intervention in the perception of six mothers of children with ASD, as well as the participation they consider having in the intervention. The study was carried out in Portugal, a country where early intervention has been regulated since 2009 in the National System for Early Childhood Intervention (SNIPI, Portuguese initials).

Regarding the benefits of early intervention in the development of their children, mothers perceived "improvement in socialization, autonomy, memory, language, motor skills, and the level of unfaltering"19. In addition, it was possible to perceive “the empowerment of the

---

17 “na operacionalização de estratégias inclusivas de ensino, de modo a atender os aprendizes com diferentes características, ritmos distintos de aprendizagem e potencialidades diferenciadas”

18 “estratégia promissora de ensino na perspectiva inclusiva”

19 “melhoria na socialização, autonomia, memória, linguagem, motricidade, e ao nível do desfralde”
parents themselves when they created strategies to enhance the children's development areas and adapted the way of dealing with changes in the behavior level”

Despite the qualitative data of relevance, regarding the mothers' perception, the study by Cossio, Pereira and Rodriguez (2017) does not present experimental data regarding the effectiveness of the program, in the same way as the study by Caldeira da Silva et al. (2003) and the early intervention programs analyzed by Lampreia (2007).

For Balestro and Fernandes (2019), the most promising pragmatic skills interventions for children with ASD are those that include the active participation of the child and their caregivers. The authors analyzed the perception of caregivers of 62 children with ASD, in Rio Grande do Sul - Brazil, regarding the functional profile of communication, and confirmed the hypothesis that “it would be possible to produce positive changes in the perspective with which parents of children with ASD perceive the communication of their children through a Program of Orientations on Communication for Caregivers (POCC) of children with ASD”.

For the authors, the results “demonstrated that the context, the attentive and responsive parental behaviors, foresee subsequent language gains in children with ASD” (Balestro; Fernandes, 2019, p. 2).

With a similar perspective, the study by Fernandes et al. (2011), sought to verify the interference of guidance to mothers of autistic children on the processes of communication and language, communicative profile and socio-cognitive performance; in addition to checking the interference of the guidelines on how mothers observe their children's abilities.

With the participation of 26 mother-child dyads, the results show that all subjects showed progress in at least one of the areas investigated, evaluating that “there was a positive impact of a systematic guidance procedure, carried out together with the children's language therapy process (and not as a substitute for it)” (Fernandes et al., 2011, p. 6).

Finally, the action research carried out by Rodriguez-Roblero (2015) deals with a one-year educational process, which took place in Costa Rica, with a father, a teacher and an autistic child, structured in 12 sessions, using games as an instrument mediation.

---

20 “o empoderamento dos próprios pais quando estes criaram estratégias para potenciar as áreas de desenvolvimento dos filhos e adequaram a forma de lidar com as alterações ao nível do comportamento”

21 For example, pragmatic communication skills, in which there is an interconnection of social and emotional aspects used in strategies of interpretation, problem solving, social information and situational expectations in spontaneous contexts. (Balestro; Fernandes, 2019).

22 “demonstraram que o contexto, os comportamentos parentais atentos e responsivos, preveem subsequentes ganhos de linguagem em crianças com TEA”

23 Houve um impacto positivo de um procedimento de orientações sistematizadas, realizadas juntamente com o processo de terapia de linguagem das crianças (e não em substituição a ela)”
The researcher's perception reached dimensions that are usually hidden in the traditional mechanistic sciences: “[... ] en realidad el amor que le tiene el padre a su hijo es lo que logra cambios de actitud, respuestas que antes no se veían, expresiones, sonrisas, alegría” (RODRÍGUEZ-ROBLERO, 2015, p. 304).

The change process was perceived by all participants: “Todos estamos cambiando, el padre, el niño y yo” (RODRÍGUES-ROBLERO, 2015, p. 305). Finally, the study showed the importance of the family in the educational process not as simple recipients, but as the protagonist.

**Final considerations**

In the analyzed articles, there is a consensus that the participation of the family of autistic people is fundamental for the success of the therapeutic or pedagogical intervention. In many unselected articles the participation of the family in the success of the intervention was not mentioned, perhaps because it is considered elementary. Even so, we insist that, due to its importance, the role of the family must always be emphasized.

In addition to that, as Baña Castro (2015) points out, it is important to overcome the biomedical model, which focuses on the pathological and the deficit, in the path of a systemic view with an educational cut. Thus, the family ceases to be just a receiver within the educational process, to become a protagonist (RODRÍGUEZ-ROBLERO, 2015).

Empirically based studies (Menotti, Domeniconi and Benitez, 2019; Benitez and Comeniconi, 2014; Balestro and Fernandes, 2019; Fernandes *et al.*, 2011) show that the learning possibilities of the autistic child increase when the family is involved in the intervention strategies.

In view of the analysis carried out in this literature review, we believe that the potential of families in the context of learning for autistic people should be affirmed, and considered an elementary principle in collective health and inclusive education actions aimed at this audience.

In view of the possible diversity of understanding of the family and its dynamics in complex realities, and the interest that the theme brings to the different areas of knowledge dealing with autism, we suggest future research in transdisciplinary perspectives.

**REFERENCES**

The relation between autism, family and learning, in articles from the scielo database (2003-2019)


The relation between autism, family and learning, in articles from the scielo database (2003-2019)


How to quote this article


Submitted: 04/02/2020
Required revisions: 10/04/2020
Approved: 03/06/2020
Published: 19/06/2020