

The influence of the family in the treatment of patient with autism spectrum disorder

A influência da família no tratamento do paciente com transtorno do espectro autista

La influencia de la familia en el tratamiento de paciente con trastorno del espectro autista

RESUMO

Objetivo: analisar as evidências científicas disponíveis na literatura sobre a influência familiar frente ao paciente com Transtorno do espectro autista (TEA) e como isso interfere em seu tratamento e desenvolvimento. **Métodos:** Foi realizado o método de revisão integrativa da literatura científica, fazendo uma síntese dos resultados obtidos. Foram utilizados estudos publicados na íntegra, indexados nas bases de dados da Scientific Electronic Library Online (SCIELO), Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS) e Base de dados em Enfermagem (BDENF), com recorte temporal de 2013 a 2023. **Resultados:** Foram elencados 15 estudos e os resultados apresentados identificam que a família tem real importância sobre o TEA, desde a conquista de um diagnóstico precoce, até ao desenvolvimento social e mental dos pacientes, por estarem cotidianamente inseridos em suas vidas. **Conclusão:** Os achados apontam que o suporte familiar é essencial, pois é fornece um ambiente seguro e previsível. É dentro desse núcleo que se torna possível a busca do melhor prognóstico potencializando estratégias de fortalecimento e adaptação.

DESCRITORES: Autismo; Enfermagem da família; Transtorno do Espectro Autista.

ABSTRACT

Objective: To analyze the scientific evidence available in the literature on family influence on patients with Autistic Spectrum Disorder (ASD) and how this interferes with their treatment and development. **Methods:** An integrative review of the scientific literature was carried out, summarizing the results obtained. Studies published in full were used, indexed in Scientific Electronic Library Online (SCIELO), Latin American and Caribbean Literature in Health Sciences (LILACS) and Database in Nursing (BDENF), with a time frame from 2013 to 2023. **Results:** Fifteen studies were listed and the results presented identify that the family has real importance on ASD, from achieving an early diagnosis, to the social and mental development of patients, as they are part of their daily lives. **Conclusion:** The findings indicate that family support is essential, as it provides a safe and predictable environment. It is within this nucleus that the search for the best prognosis becomes possible, enhancing strengthening and adaptation strategies.

DESCRIPTORS: Autism; Family nursing; Autistic Spectrum Disorder.

RESUMEN

Objetivo: Analizar la evidencia científica disponible en la literatura sobre la influencia familiar en pacientes con Trastorno del Espectro Autista (TEA) y cómo ésta interfiere en su tratamiento y desarrollo. **Métodos:** Se realizó una revisión integradora de la literatura científica, resumiendo los resultados obtenidos. Se utilizaron estudios publicados en su totalidad, indexados en las bases de datos Biblioteca Científica Electrónica en Línea (SCIELO), Literatura Latinoamericana y del Caribe en Ciencias de la Salud (LILACS) y Base de Datos en Enfermería (BDENF), con un marco temporal de 2013 a 2023. **Resultados:** se listaron 15 estudios y los resultados presentados identifican que la familia tiene una importancia real en los TEA, desde lograr un diagnóstico precoz, hasta el desarrollo social y psíquico de los pacientes, ya que forman parte de su día a día. **Conclusión:** Los hallazgos indican que el apoyo familiar es fundamental, ya que proporciona un ambiente seguro y predecible. Es dentro de este núcleo que se hace posible la búsqueda del mejor pronóstico, potenciando estrategias de fortalecimiento y adaptación.

DESCRIPTORES: Autismo; Enfermería familiar; Trastorno del espectro autista.

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INTRODUCTION

Autism or Autism Spectrum Disorder (ASD) is characterized by neurodevelopmental disorders, with a higher prevalence of symptom onset in early childhood, which falls between birth and 6 years of age and its basis is essentially genetic and cerebral. Its worldwide prevalence is around 10/10,000 children, being higher among males; for every one girl, five boys are autistic.¹

There are two essential characteristics that can define the autistic, the first of which is social isolation, and the second, the presence of stereotyped behaviors and the act of insisting on the same things. In addition, it is a mental state in which the person with it tends to close in on himself and the outside world.²

The federal government has shown efforts to care for the autistic population and their families, especially in terms of rights, based on the National Policy for the Protection of the Rights of Persons with ASD, which, among other issues, guarantees early diagnosis, multidisciplinary care and access to information that helps in diagnosis and treatment.³

The family is the child's first social group and the primary setting for their care; having the ability to accommodate their needs, with a view to supporting and promoting their development potential.^{4,5} The birth of a child with special needs, such as a child with ASD, can trigger a complex family crisis, which changes the pattern of the family's life cycle and can cause intense anxiety and stress.⁶ Research shows that interacting with a child with autistic characteristics can trigger a feeling of failure in pa-

rents, given the difficulties experienced in contact with a baby who seems to ignore their existence, not showing explicit interest in parental figures.^{7,8}

This study is justified by identifying that in the health literature there is a recurrence of studies on autism, however few are aimed at exploring the perspective in the family context.⁹ It is understood that in addition to identifying the difficulties encountered by these families, it is necessary to invest in research that focuses on the processes developed by families in search of adaptation to the situation, highlighting their potential.¹⁰

In view of the above, the present study aims to answer the following guiding question: what are the family's difficulties and challenges in the inclusion of patients with ASD and how does this directly interfere with their treatment?

METHOD

The developed study corresponds to a research with design in the integrative review of the scientific literature. There are six phases of the integrative review process, in which, the 1st phase defines the guiding question, which was the basis for determining which studies would be included or not; the 2nd phase is the one that, taking into account the guiding

question, starts to carry out the search and sampling in the literature, determining the criteria for this; in the 3rd phase, data is collected from the selected materials and, similarly to the 4th phase, a critical analysis of the studies is carried out; the 5th phase makes the interpretation and synthesizes the results, making the discussion of what was collected; finally, the 6th phase presents the integrative review itself, using Evidence-Based

Practice as an instrument.

The guiding question of this review was prepared based on the PICO strategy, with the letter “P” corresponding to the study population, the letter “I” to the phenomenon of interest and the “Co” to the context.¹¹ Based on this strategy, the PICO structure of this study was organized as follows:

ACRONYM	DEFINITION	DESCRIPTION
P	Patient or problem	Patients with ASD.
I	Intervention	Good family life.
C	Control or comparison	Patient without family/social inclusion and intra-family problems.
O	Outcome	Patients with good acceptability, development and healthy and strengthened family relationships.

TITLE	AUTHOR	OBJECTIVE	METHOD	PUBLICATION
Daily life of families living with childhood autism. (Cotidiano de famílias que convivem com o autismo infantil.)	Zanatta EA, Mene-gazzo E, Guimarães AN, Ferraz L, Motta MGC. ¹²	Knowing the daily life of families living with childhood autism.	Qualitative, descriptive-exploratory research.	Rev. Baiana de enfermagem. vol. 28 n°. 3, 2014.
Nursing diagnoses and interventions in children with ASD: perspective for self-care. (Diagnósticos e intervenções de enfermagem em crianças com TEA: perspectiva para o autocuidado.)	Magalhães JM, Sousa GRP, Santos DS, Costa TKSL, Gomes TMD, Rêgo Neta MM, et al. ¹³	To describe nursing diagnoses and interventions in children with ASD based on nursing taxonomies and self-care theory.	Exploratory and descriptive study.	Rev. Baiana de enfermagem. vol. 36, 2022.
Family experiences in the discovery of Autistic Spectrum Disorder: implications for family nursing. (Vivências familiares na descoberta do Transtorno do Espectro autista: implicações para a enfermagem familiar.)	Bonfim TA, Gi-con-Arruda BCC, Hermes-Uliana C, Galera SAF, Marcheti MA. ¹⁴	To describe the family's experience in the process of discovering the diagnosis and starting treatment for children with Autism Spectrum Disorder.	Qualitative, descriptive study.	Rev Bras Enferm. vol. 73, 2020.
Child with autism spectrum disorder: care from the family perspective. (Criança com transtorno do espectro autista: cuidado na perspectiva familiar.)	Mapelli LD, Barbieri MC, Castro GVDZB, Bonelli MA, Wernet M, Dupas G. ¹⁵	To learn about the family's experience in caring for children with Autism Spectrum Disorder and discuss possibilities for health care.	Descriptive, qualitative research.	Esc Anna Nery. vol. 22 n°. 4, 2018.
The psychoanalytical listening of the family facing the diagnosis of autism in the child. (A escuta psicanalítica da família frente ao diagnóstico de autismo da criança.)	Almeida ML, Neves AS. ¹⁶	To investigate the family's listening to the child's diagnosis of autism.	Psychoanalytic study.	Ágora. vol. 23 n°. 3, 2020.

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Childhood autism: impact of diagnosis and repercussions on family relationships. (Autismo infantil: impacto do diagnóstico e repercussões nas relações familiares.)	Pinto RNM, Torquato IMB, Collet N, Reichert APS, Souza Neto VL, Saraiva AM. ¹⁷	To analyze the context of disclosure of the autism diagnosis and its impact on family relationships.	Qualitative study.	Rev Gaúcha Enferm. vol. 37 n°. 3, 2016.
Contributions of alternative communication in the development of communication in children with ASD. (Contribuições da comunicação alternativa no desenvolvimento da comunicação de criança com TEA.)	Montenegro ACA, Leite GA, Franco NM, Santos D, Pereira JEA, Xavier IALN. ¹⁸	To present the contributions of using a high-tech Augmentative and Alternative Communication system in the development of the communication skills of a child with ASD.	Case study.	Audiol Commun Res. vol. 26, 2021.
Coparenting in the family context of children with ASD. (Coparentalidade no contexto familiar de crianças com TEA.)	Portes JRM, Vieira ML. ¹⁹	To understand the perception of fathers and mothers with children diagnosed with autism spectrum disorder, of their co-parental relationship.	Descriptive exploratory study.	Psicol. estud. vol. 25, 2020.
Diagnosis of autism in the 21st century: evolution of domains in nosological categorizations. (Diagnóstico de autismo no século XXI: evolução dos domínios nas categorizações nosológicas.)	Fernandes CS, Tomazelli J, Girianelli VR. ²⁰	To analyze the evolution of the diagnosis of autism in the 21st century, from the domains and subdomains on which nosological categorizations are based.	Documentary research.	Psicologia USP. vol. 31, 2020.
Children with ASD: perception and experiences of families. (Filhos com TEA: percepção e vivências das famílias.)	Monhol PP, Jastrow JMB, Soares YN, Cunha NCP, Pianissola MC, Ribeiro LZ, Santos JA, Bezerra IMP. ²¹	To analyze the experience of families with children with Autistic Spectrum Disorder.	Exploratory study with a qualitative approach.	J Hum Growth Dev. vol. 31 n°. 2, 2021.
Mothers of children with autistic disorder: perceptions and trajectories. (Mães de crianças com transtorno autístico: percepções e trajetórias.)	Ebert M, Lorenzini E, Silva EF. ²²	To know the perceptions of mothers of children with autism regarding the alterations presented by the child and the trajectories covered in the search for the diagnosis of autism.	Exploratory, descriptive study with a qualitative approach.	Rev Gaúcha Enferm. vol. 36 n°. 1, 2015.
Family burden and children with Autism Spectrum Disorders: caregivers' perspective. (Sobrecarga familiar e crianças com Transtornos do Espectro do Autismo: perspectiva dos cuidadores.)	Misquiatti ARN, Brito MC, Ferreira FTS, Assumpção Junior FB. ²³	To evaluate the overload of family caregivers of children with autism spectrum disorders, according to the perception of the caregivers themselves.	Cross-sectional research.	Rev CEFAC. vol. 17 n°. 1, 2015.
Becoming a family of a child with Autism Spectrum Disorder. (Tornar-se família de uma criança com Transtorno do Espectro Autista.)	Machado MS, Londero AD, Pereira CRR. ²⁴	Reflect on becoming a family of a child with Autism Spectrum Disorder (ASD) based on the repercussions of the disorder on families, their characteristics, their future perspectives and how they recognize themselves in this context.	Qualitative and exploratory study.	Contextos Clínicos. vol. 11 n°. 3, 2018.
The importance of the family in the care of the autistic child. (A importância da família no cuidado da criança autista.)	Filho ALMM, Nogueira LANM, Silva KCO, Santiago RF. ²⁵	To analyze the family's participation in the care of the autistic child and describe the reaction of the family members to the diagnosis.	Descriptive, exploratory, qualitative study.	Rev Saúde em Foco. vol. 3 n°. 1, 2016.
Assistance to families of children with Autistic Spectrum Disorders: perceptions of the multidisciplinary team. (Assistência às famílias de crianças com Transtornos do Espectro Autista: percepções da equipe multiprofissional.)	Bonfim TA, Giacon-Arruda BCC, Galera SAF, Teston EF, Nascimento FGP, Marcheti MA. ²⁶	Summarize the care provided by health professionals, at different levels of care, to families of children with Autistic Spectrum Disorders.	Qualitative study	Rev Latino-Am. Enfermagem. vol. 31 n°. 3781, 2023.

The collected data come from the following scientific databases: Scientific Electronic Library Online (SCIELO), Latin American and Caribbean Literature in Health Sciences (LILACS) and Database in Nursing (BDENF). After establishing the inclusion and exclusion criteria, it resulted in 15 articles published in full with a methodological approach between the years 2013 to 2023. In the search strategy, the following terms were used according to the Health Sciences Descriptors (DeCS): Autismo (Autism); Enfermagem da família (Family nursing); Transtorno do Espectro Autista (Autistic Spectrum Disorder). To perform the crossing between the terms, the Boolean logic AND and OR were used in order to obtain the greatest possible number of results.

As this is an integrative review study, approval by the Research Ethics Committee (CEP) was waived in accordance with Resolutions 466/12 and 510/16 of the National Health Council.

RESULTS

The articles selected for this study are described in the table below, with title, date of publication, author, place of publication, methodology and objectives of each one of them.

DISCUSSION

In order to elucidate the discussion around the guiding question, after reading, analyzing and collecting data from the 15 selected articles, 5 categories were created, in which category 1 addresses the diagnosis and how the family perceives and confronts it; category 2 deals with the importance of the family for the diagnosis, treatment and development of the person with ASD; category 3 portrays the autistic person and the consequences of the intrafamilial relationship; category 4 offers strategies for coping with the situation and category 5 addresses how nursing professionals should deal with ASD.

CATEGORY 1: ASD AND FAMILY DIAGNOSIS

The daily interaction of parents and family with a child gives them the opportunity to recognize behaviors that differ from those observed in other known children. Although they may not understand the exact nature of these differences, they are aware that something is outside the norms considered normal, especially when these different behaviors emerge after a period of normality.¹²

Primarily, the family ends up interpreting the manifested signs as innate, with no relation to specific disorders. Unexpected reactions due to discomfort or setbacks are just characteristics of the child's personality, in addition, the duality of opinions in the family social circle adds even more difficulties to the process.¹⁵

When the first signs appear and the family begins to notice the first changes in the child's behavior, difficulty arises in recognizing the possibility of a health problem and in understanding whether such behaviors or changes are individual characteristics or simply part of the phase they are in. This interpretation may be linked to the fear that permeates this initial phase and family relationships, especially related to the future that the family envisioned for the child. In view of this, parents begin to be more attentive to behaviors when they realize that the child's development is not occurring as expected and the difficulty of interaction expressed by the child with ASD, makes the family turn its eyes to a possible diagnosis.^{15,14}

And it is at this moment, with marked behaviors in situations in which the child seeks to signal their discontent and discomfort in social interactions, such as intense noise in open spaces and inflexibility in changing routines, that they begin to integrate evidence for a probable diagnosis.¹³

However, as ASD is a spectrum, the

dimension is expanded and generalized, causing the diversity of symptoms that unfold during the initial years of an individual's life, to harbor an immediate diagnostic delay, since the exams are not specific, but purely based on the child's history which, added to the precariousness of specific training of professionals who deal with the disorder, make the achievement of a diagnosis become distant and full of doubts.^{16,17}

CATEGORY 2: THE IMPORTANCE OF THE FAMILY

As seen earlier, parents and families are the first to notice that their children exhibit different behaviors that do not fit the standards considered normal, and that is why parental involvement in the diagnosis of autism is extremely important.¹²

The family plays a key role in detecting ASD in children, as it is in the family nucleus that it becomes possible to notice the delay in speech and language and the deprivation of interaction with other children, for example. Generally, the mother is the first person who perceives changes in behavior and/or child development, and such changes are noticed from the first months of the child's life.²²

In order for the detection of these events to be possible, it is imperative that there be appropriate parental sensitivity.¹⁵ It is not a question of attributing complete responsibility for the diagnosis to parents⁹, but to recognize the signs of psychological difficulties faced by the child, as this information will help in the hypothesis and in the early diagnosis.²²

It is noteworthy that, although it is a syndrome without cure so far, it is crucial to highlight that an early diagnosis can lead to advances in behavior, motor skills, interpersonal interaction and communication skills of the child. However, it is fundamental that the parents can stimulate it, overcoming possible different views

and integrating it into the social environment. 16 And these are the ones who play a key role in the therapeutic process and, when trained and guided, contribute to the effectiveness of the intervention. Furthermore, early interventions that make use of methods such as Augmentative and Alternative Communication (AAC), especially in the first three years of life, favor the child's linguistic development, stimulate their initiative and communicative intention and promote their adequate development and interaction in their social contexts, regardless of the time required to achieve autonomy in verbal communication. It is within the family that the best possibilities for autistic growth are identified.^{18,6}

Family interaction plays a crucial role in the life of a child who has received an ASD diagnosis, as it is their first relational context. This interaction has a significant influence in determining human behavior and shaping the child's personality.²¹

CATEGORY 3: THE AUTIST AND THE INTRAFAMILY RELATIONSHIP

The experience of family members during the process of diagnosis and initiation of treatment can be divided into two distinct phases. The first phase occurs before the diagnosis, when parents or the school realize that the child's behaviors are not appropriate for his age, leading them to start looking for explanations. The second phase occurs after the diagnosis and the start of treatment, bringing relief in relation to the previous period and requiring a reorganization of the family system in the face of the new context.¹⁴

In this moment of adaptation, the family needs to seek to understand and bring improvements to the child's development²¹, because she is never prepared to deal with this reality, but mutual support is essential in order to provide adequate treatment, develop skills to deal with the situation and promote a

good quality of life for the child.²⁵

Within the family nucleus, relationships are seen as a means of enabling the child with ASD to deal with broader social interactions. The intentional use of relationships with siblings, for example, aims to prepare them to relate to society in general¹⁵, it is in living together that each reaction, manifestation and symptom is learned on a daily basis, and it is there that acceptance and development are found.¹²

CATEGORY 4: COPING STRATEGIES

Raising a child with ASD is hard work. A study by Misquiatti²³, revealed that people who are part of families with these characteristics have a greater physical and mental overload than the others. It is then that, upon noticing this, they choose to seek social support that can help positively and bring coping strategies.²⁶

The social environment has great influence at this moment, for this reason, it is extremely important to search for places with real help. Participating in family groups in a similar situation, for example, makes it possible to share good and bad experiences, makes use of tricks to deal with difficulties and a new look at this trajectory of diagnosis and care for the individual with ASD.¹⁵

In addition, institutions such as the Association of Parents and Friends of the Disabled (APAE - Associação de Pais e Amigos dos Excepcionais) or the Association of Friends of the Autistic (AMA - Associação de Amigos dos Autista), seek to offer moments of knowledge and interaction, resolving doubts and making families and individuals with ASD more qualified to develop healthy ways of dealing with their difficulties, without relying solely on professional support, making them protagonist agents in their own lives, demonstrating the ability to create strategies to face the challenges related to the disorder, even when they lack external support and support.^{12,6}

CATEGORY 5: THE NURSING PROFESSIONAL AND TEA

On the other hand, the professional who receives this family must be prepared. Most families, when seeking help, are faced with professionals who know little or nothing, or who, when offering help, do so in a timely manner, with activities planned according to each child and focused on him/her alone, forgetting that there are several circumstances shuddering behind that must be remedied.^{19,21}

In this sense, it is beneficial to use strategies that promote the adoption of theoretical models based on the systemic perspective of family nursing, such as the FCC (Family-Centered Care), as this helps nurses to establish therapeutic dialogues with families. Nursing, as a link in the multidisciplinary team, can contribute to the use of evaluation and intervention models, as well as help other professionals in the team to interact with families. The Calgary Family Assessment and Intervention Model (CFIM) and the Family Intervention Program (FIP) are systematic frameworks that help nurses work with families, assessing their needs and proposing interventions that seek to meet them, in addition to valuing their skills and resilience in the face of the illness process.^{13,14}

Relatives of children with ASD need both emotional support to deal with the consequences of the disorder in the family's daily life, and professional guidance to know how to act with the child.⁶

It is essential to demonstrate that they are not alone and that the difficulties they face are shared by other families who experience the process of psychological treatment. It is essential to allow them the opportunity to express their anxieties, feelings, anxieties, frustrations and fears in relation to their children, receiving the necessary support from the professionals involved. This helps them feel more secure and motivated to raise their autistic children in the best possible way.¹²

CONCLUSION

It is concluded that, in many ways, family support is essential for people with autism. First, the family is the main source of emotional and social support for the person with autism. In addition, the family can provide a safe

and predictable environment, which is fundamental for them. It is within the family that it becomes possible to identify the signs of ASD early, leading to a search for help in specialized services that can offer a diagnosis and initiate the necessary interventions early in the development of the disorder, which

provides a more favorable prognosis for the patient, leading to the understanding that this does not mean the cure, but the search for the best development of the person with ASD.

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