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INTEGRATIVE LITERATURE REVIEW

FAMILY ENVIRONMENT AND THE DEVELOPMENT OF A CHILD WITH AUTISM O AMBIENTE FAMILIAR E O DESENVOLVIMENTO DA CRIANÇA COM AUTISMO EL ENTORNO FAMILIAR Y EL DESARROLLO DE UN NIÑO CON AUTISMO

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ABSTRACT

Objective: to identify evidence available in the literature about how the family environment is able to influence the development of a child with autism spectrum disorder. Method: this is a bibliographic, descriptive study, characterized as an integrative literature review of studies published in the period from January 2007 through December 2017, in the databases Medline and WebOfScience. Data collection occurred between March and May 2018 with controlled descriptors included in DeCS, in English, Portuguese and Spanish. The studies were analyzed considering author, objectives, methodology and year of publication, presenting the results in the form of a figure. Results: situations such as parenting styles, the participation of family members in the daily life of the child, socioeconomic situations and the individual culture have great influence on the development of the child with ASD. Conclusion: new studies related to the theme should be developed aiming to improve the quality of life of children with autism spectrum disorder and their families. Descriptors: Autism; Autism Spectrum Disorder; Child Development; Family; Child; Family Relations.

Objetivo: identificar evidências disponíveis na literatura sobre como o ambiente familiar é capaz de influenciar o desenvolvimento da criança com transtorno do espectro autista. Método: trata-se de um estudo bibliográfico, descritivo, tipo revisão integrativa de literatura de estudos publicados no período de janeiro de 2007 a dezembro de 2017 nas bases de dados Medline e WebOfScience. Realizou-se a coleta de dados entre os meses de março e maio de 2018 com descritores controlados contemplados no DeCS, nos idiomas inglês, português e espanhol. Analisou-se os estudos considerando autoria, objetivos, metodologia e ano de publicação, apresentando-se os resultados em forma de figura. *Resultados:* observou-se que situações como estilos parentais, participação dos familiares na vida diária da criança, situações socioeconômicas e a cultura individual possuem grande influência no desenvolvimento da criança com TEA. Conclusão: espera-se o aparecimento de novos estudos relacionados ao tema com o intuito de melhorar a qualidade de vida das crianças com transtorno do espectro autista e dos familiares. Descritores: Autismo; Transtorno do Espectro Autista; Desenvolvimento Infantil; Família; Criança; Relações Familiares.

RESUMEN

Objetivo: identificar la evidencia disponible en la literatura acerca de cómo el entorno familiar es capaz de influir en el desarrollo de los niños con trastorno del espectro autista. Método: este es un estudio bibliográfico, descriptivo, tipo revisión integradora de la literatura de estudios publicados en el período comprendido entre enero de 2007 y diciembre de 2017 en las bases de datos Medline y WebOfScience. La recopilación de datos ocurrió entre los meses de marzo y mayo de 2018 con los descriptores controlados incluidos en DeCS, en inglés, portugués y español. Se analizaron los estudios considerándose autor, objetivos, metodología y año de publicación, presentando los resultados en forma de una figura. Resultados: se observó que las situaciones tales como estilos de crianza de los hijos, la participación de los miembros de la familia en la vida cotidiana de los niños, su situación socioeconómica y la cultura individual tienen gran influencia sobre el desarrollo de los niños con TEA. Conclusión: se espera la aparición de nuevos estudios relacionados con el tema, con el objetivo de mejorar la calidad de vida de los niños con trastorno del espectro autista y sus familias. Descriptores: Transtorno Autístico; Trastorno Del Espectro Autista; Desarrollo infantil; Familia; Niño; Relaciones Familiares.

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INTRODUCTION

Autism spectrum disorders (ASD) are a set of neuropsychiatric clinical onset in childhood, represented by limitations in the development which entail losses in social and communicative skills and other cognitive aspects, characterized by restricted,

aspects, characterized by restricted, repetitive and stereotyped patterns of behavior, interests and activities, including social reciprocity, ranging from abnormal social approach through difficulty to share interests, emotions and affection.^{1,2}

Its etiology is not completely known, so there is not a specific biological marker; however, it has multiple etiologies, such as genetic and neurobiological factors, in addition to the interaction with the environment.³⁻⁵

The symptoms vary in severity and are usually identified around two years of age, although they may occur earlier. Furthermore, the symptoms show changes during development, which can be masked by compensatory mechanisms in some contexts, thus, an important part of the diagnosis is the retrospective analysis.²

Within the team of support and encouragement to patients with autism, the family occupies an indispensable function, since, besides being the main context of socialization of individuals and the first mediator between the subject and the culture, it is characterized as a systemic and dynamic unit that interferes and suffers interference from each one of its members and the environment.⁶⁻⁹

The relations between the members of a family significantly influence the behaviors, beliefs, feelings and, especially, the development of each member according to the principle of circularity, characterized by a bidirectional and dynamic interaction within the family system.^{7,10}

In the context of a family whose child has ASD, there are several difficulties to be faced,

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such as searching for the best type of treatment, shortage of specific health services, hope for the unknown, in addition to the stigma imposed by society. The family relations may suffer changes that entail changes in the child's development.²⁻⁴

Therefore, when considering the importance of family relations in the development of individuals with ASD, there is a need to examine what has been produced on this subject in order to provide subsidies that are relevant to the organization and preparation of effective actions focused on integral care in mental health.

OBJECTIVE

◆ To identify the evidence available in the literature about how the family environment influences the development of the child with spectrum disorder.

METHOD

This is a bibliographical, descriptive study, characterized as an integrative literature review, which allows gathering and synthesizing studies on certain topic, in a systematic and organized way, to deepen the knowledge and enable general conclusions about the investigated issue.¹¹⁻²

following steps were used systematize the research: identification of the theme and elaboration of the research question, definition of the descriptors and databases to be used, the establishment of exclusion inclusion and criteria manuscripts, identification of studies performing the first selection from the reading of the title and abstract, extraction of information, analysis and categorization of data collected and synthesis of information. Figure 1 shows the process followed.

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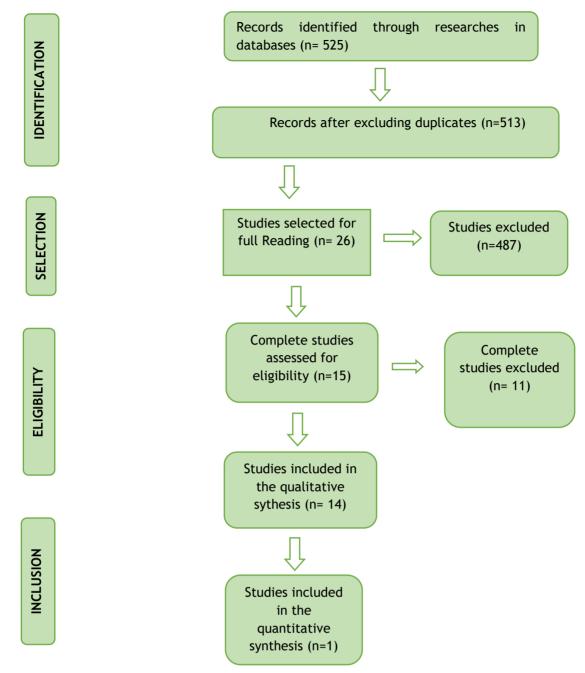


Figure 1. Flowchart of the methodological steps followed to select the studies. Ribeirão Preto (SP), Brazil, 2018.

The research guiding question that emerged was: "What is the available scientific knowledge about the influence of family on the development of the child with ASD?".

The inclusion criteria were: primary articles that described family relationships and how they affect the development of children with ASD; articles published in English, Portuguese and Spanish, produced in the period from January 2007 through December 2017; studies published in journals indexed in the databases: PsycINFO, MEDLINE (Medical Literature Analysis and Retrieval System Online) via VHL (Virtual Health Library) and Web of Science. The search for articles occurred in the period from March to April 2018.

There was exclusion of articles that did not include children or families, articles that assessed behavioral activities, articles describing interventions and therapies in autistic individuals, literature review articles, articles that reported the genetic or

neurochemical functions, duplicate studies and those not available free of charge for online access.

The controlled descriptors (Decs) applied were the terms Autism Spectrum Disorder (ASD), child development and family in multiple combinations, according to the researched terminology in the indexer (Theasurus of APA, Mesh or VHL).

In PsycINFO database, there were 154 publications with the descriptor "Autism". After applying the filter "articles", 60 works remained. Of these, eight were pre-selected by reading the title. Two articles were included for subsequent full reading after analyzing their abstract. After fully reading the two articles, none of them responded to the question of the present study, thus being excluded.

In Medline database, there were 354 publications with the descriptors "Autism Spectrum Disorder", "child development" and "family". After applying the language filters,

the period of publication (last 10 years) and "children", 207 publications remained. Of this total, 63 articles were selected by reading the title. After analyzing the abstracts, 21 articles were selected for full reading. In the end, 13 articles were included in the study.

The initial search in Web of Science database returned 17 documents. After applying the filters, 13 studies remained, five of which met the inclusion criteria. Of them, two articles were unavailable online, thus requesting the entire document to the authors by means of electronic mail, obtaining, in this way, access to one of them. Therefore, three articles were selected for full reading and, after this step, two articles remained in this literature review.

The full analysis of the studies allowed extracting the information according to the

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complete authorship of the article, authors' origin, objective of the study, type of study, sample, data collection instruments, procedures and the main results. The synthesis occurred descriptively.

RESULTS

This literature review included 15 studies in the English language, the majority originated in the United States¹³⁻²⁰, two in the Netherlands²¹⁻², two in the United Kingdom²³⁻⁴ and one in each of the following countries: Belgium²⁵, India²⁶, Canada²⁷. All studies were cross-sectional, 14 were qualitative^{8,13-15,17-19,21-23,25-28}, and one article was quantitative²⁰. There were no national studies about the topic. Figure 2 shows the authorship, the objectives, the types of study and the main results of the reviewed studies.

Authors/Year	Objective	Type of study	Main results
Blanche EI; Diaz J; Barretto T; Cermak AS/ 2015	To understand the experiences of caregivers of Latin families of children with ASD, including daily activities, coping strategies and use of services.	Qualitative; cross-sectional	The family culture interferes on the experiences and the caregiver's relationship with a child. Four major themes were identified in relation to caregivers' experiences of Latin families with a child with ASD who lived in the United States: 1-The difficulty dealing with the diagnosis; 2-The difficulty dealing with the stigma and consequent isolation of the family from the community; 3-The fundamental role of mothers in the family routine change; and 4-Language barriers and lack of knowledge on the use of services. The family culture influences all aspects.
Griffith GM; Hastings RP; Petalas MA; Lloyd TJ/ 2014	To analyze the emotional dimensions of intrafamily relations in families with children with ASD and compare the emotion expressed by mothers of children with ASD and neurotypical children	Quantitative cross-sectional	Mothers tend to be more critical and less cordial in the form they treat their child with ASD when compared with how they treat their nurotypical child. There was no difference regarding expressed emotion and emotional involvement with the children
Van Steijn DJ; Oerlemans AM; Ruiter SW; Van Aken MAG; Buitelaar JK; Rommelse NNJ/2013	To explore the influence of the child diagnosis and of the ASD and/or ADHD of parents	Qualitative cross-sectional	Fathers and mothers tend to apply a less authoritarian parenting style for neurotypical children and a more permissive parenting style in relation to the affected children. There was greater permissiveness toward neurotypical children when parents had high symptoms of ASD or ADHD.
Bekhet A; Johnson NL; Zauszniewski JA/2012	O analyze the effects of the caregiver's overload and positive cognitions in the caregiver's development/resilie nce	Qualitative cross-sectional	Positive cognitions strengthened the effects of load on the caregiver's development, thus, interventions to promote positive cognitions may help caregivers of people with autism feel less overwhelmed and with more features over time.
Cheuk S; Lashewicz B/ 2015	To analyze how parentes of children with ASD realize they are deliang with the situation in comparison to parentes of neurotypical	Qualitative cross-sectional	Parents of children with ASD feel "pangs of envy" in relation to parents of children with typical development, but they are alert to the development of their children and convey a feeling of gratitude for the abilities and personality of their children in the midst of the appreciation for trials and triumphs, with this, they end up stimulating the development.

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	children		
Van Tongerloo MAMM; Wijngaarden PJM; Van der Gaag RJ; Lagro- Janssen ALM/2015	children To determine the experiences of parentes of children with ASD and the type of support they would like to receive from primary care	Qualitative cross-sectional	Parents feel guilt or feeling of having failed in raising their children with ASD and feel they have less time to devote to other the neurotypical children. Most parents reported feeling the burden of care for the child with ASD, mainly in what concerns the adaptation of the child's daily activities, which led to the withdrawal of jobs, social isolation and to physical and mental stress. Both fathers as mothers tend to apply a more permissive parenting style in relation to the affected children, which increases the risk of making it even more difficult to deal with the challenges of behavior.
Estabillo JA; Matson JL; Jiang X/ 2016	To analyze the relation of ASD diagnosis for the Family and the appearance of symptoms in small children with and without ASD	Qualitative cross-sectional	Children who have relatives with ASD are more likely to develop symptoms of autism according to their behaviors. Although these children have not been diagnosed with ASD, children with a family history tend to present greater symptoms of ASD.
Hall HR; Graff JC/2012	To analyze maladaptive bahaviors of children with autism, family support, parental stress and parents' coping	Qualitative cross-sectional	There is an association between increased maladaptive behaviors and increased parental stress. Parents reported that maladaptive behaviors of externalization of their childrne were higher than their internalizing behaviors.
Hartley SL; Barker ET; Seltzer MM; Greeberg J; Floyd F; Orsmond G/2010	To analyze the occurence of divorce and its moment in parentes of children with ASD and those whose children do not have ASD	Qualitative cross-sectional	Parents of children with ASD had a higher divorce rate than the comparison group. The risk of divorce begins to decline in the child's late childhood to parents of children without disabilities and is extremely low at the time the child is a young adult. In contrast, the risk of divorce for parents of children with ASD remains marked throughout adolescence and early adulthood. For parents of children with ASD, the maternal age at which the child with ASD was born (younger) and the birth order (when the child was born later) predicted significantly the divorce. One of the explanations is that neurotypical children begin their own independent lives and parental demands and stresses often decrease, providing a renewed focus on the marital relationship since parents of children with ASD generally continue to have a "full nest" and high levels of parental demand and stress subsequently, they may continue to experience marital tension early in their child's adulthood.
Hill-Chapman CR, Herzog TK, Maduro RS/2013	To explore the relationship between symptoms of the child with ASD and parents' stress including parental alliance	Qualitative Cross-sectional	Higher parental stress relates to low parental alliance. The high infant symptomatology positively relates to parental alliance focused on the child, not focused on the parents. An evaluation of the partner as competent and committed to the child is able to partially mediate the relationships between parental stress and the high severity of atypical child behavior.
Johnson NL, Simpson PM/2013	To understand the ramifications of results of the lack of participation of a spouse/father in a s tudy focused on stress and family functioning	Qualitative Cross-sectional	Mothers of children with ASD are at risk of social isolation and stress when negotiating family functions with the child's fathers. Parents may not have time to participate in surveys, as well as they may not have time to participate in childrelated decisions on a day-to-day basis. The lack of support from the father and other family members contributes to stress.
Zablotsky B, Bradshaw CP, Stuart EA/2013	To analyze the level of stress and psychological well- being of mothers of children with ASD	Quantitative Cross-sectional	Mothers of children with ASD are at increased risk for unstable mental health and high levels of stress. Variables such as lower income, black children and greater complications/comorbidities of ASD in the child increased this risk. Mothers who had three or more children have this risk reduced. Mothers who have a high level of stress

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			or depression may exhibit decreased parental skills, negatively affecting the child's physical and mental health. Social and emotional support is a coping strategy that assists in reducing risk.
Petalas MA, Hastings RP, Nash S, Reilly D, Dowey A/2012	To understand the perspective of teenage siblings who grow up with a sibling with ASD on their circumstances and experiences	Qualitative Cross-sectional	Neurotypical siblings present certain difficulties, constraints, stress and concerns regarding their siblings with ASD, but, on the other hand, they also present a protective sense and a great empathy. They say they would like the ASD siblings to be "normal" people to be happier, but they accept the current conditions.
Meirsschaut M, Warreyn P, Roeyers/2011	To compare the interactive behavior of mothers in relation to the child with ASD and to the neurotypical child and the child's social behavior	Qualitative Cross-sectional	Mothers differ in their ability to respond, but not in their initiatives toward children. Children with ASD and their siblings without ASD were equally responsive, but children with ASD were more imperative in relation to the caregiver. Mothers adjust their social behavior specifically to the age and developmental characteristics of their different children and less specifically to the characteristics of autism.
Kelly AB, Garnett MS, Attwood T, Peterson C/2008	To analyze the potential impact of conflict and family cohesion in children with ASD	Qualitative Cross-sectional	Family conflicts increase anxiety and depression, which predicted the severity of ASD. The quality of the family relationship predicted the symptomatology of ASD. After diagnosis and/or therapy, the symptomatology of ASD minimally predicted family conflict.

Figura 2. Características dos artigos incluídos na revisão integrativa de literatura. Ribeirão Preto (SP), Brasil, 2018.

DISCUSSION

This study aimed to identify the evidence available in the literature about how the family environment influences the development of children with autism spectrum disorder.

The studies varied regarding goals; however, they evidenced various intrafamily situations that may influence the development of the child with ASD.

All articles included in this study used the cross-sectional cut as method in relation to the time of data collection. Since social relations and human development variables that are in constant transformation and adaptations, the ideal, to extract a full understanding of these situations, would be gathering the information over time, using the method of longitudinal research, because it combines the individual variables and the social variables of the processes of interactions with the variability in time. 10,29

The social dimension of intrefamily relations is essential to understand how the development of children occurs. 10,23

The parental style is a very important variable for the development of the child. The parental style is characterized as behavioral and affective aspects of parents expressed in the interaction given by the way of educating children and directly and indirectly influences the child's response.³⁰ This literature review showed that some families tend to have a creation style more permissive and protective in relation to children with ASD.^{14,31,21-2,32}

Permissive parenting style ends up resulting in disabilities to define rules and limits for the child, as well as establishes a few demands of responsibility. In addition, parents are very tolerant, affectionate and receptive to their children, tending to meet any demands of the child.³⁰

This parental style may predominate among families who have children with ASD due to lack of information for parents in relation to their child's disorder, the proper treatment, parents' difficulty dealing with their child's episodes of crises and the transformations of expectations regarding the child's future after the diagnosis. ^{21,27,30,33}

A negative dimension of permissive parenting style is the excessive protection of children, the lack of stimuli to develop communicative, social and cognitive abilities and even social isolation, which is a reality experienced by many families with children with ASD and that eventually leads to a dysfunctional development. 14,21-2,30,33

Parental alliance, in relation to the child's daily activities, is the next variable capable of influencing the development of the child with

Parental alliance is a part of the conjugal relationship characterized as the degree of involvement and cooperation of each one of the parents in the child's education process and assumes the role of mediator between family functioning and the child's development. 18,26,33-4

Most of the studies included in this review highlighted the frequent presence of mothers

as primary caregivers and the distancing of fathers, as well as other family members, characterizing a weak parental alliance. 4,13-5, 16-19,21,23,25,35

In the literature, the almost exclusive presence of mothers as caregivers of children with ASD and the distancing of other family members results in maternal overload and stress, social isolation, lack of incentives for children's social skills and magnification of symptoms, leading to a difficulty in the development of the child with ASD.^{8,13-5,17-21,23,26,35}

The ASD symptomatology directly relates to the quality of family relationships. Negative relationships characterized with a low parental alliance increases the family conflicts and, consequently, increases the presentation of symptoms such as anxiety, depression or stress in the child.^{26,33}

The culture of each family also has an important role in all of the variables that influence the child's development, because it involves the parental style, the way they relate, the role of each family and individual personality.¹⁴

The neurotypical siblings of children with ASD are actor of great influence in the development of the child with ASD, because, in addition to interfering in the parental alliance, they have their own relationships with children affected by ASD, i.e., the way they relate may interfere positively or negatively in their development.²⁴

Although there is a stressful factor in relation to the symptoms of children with ASD, their neurotypical siblings tend to maintain a protective and empathetic sense, helping children with ASD in their needs, which helps positively in the development, since children with ASD do not have large social support in relation to friendships. 14,18,26,28

Another factor related to the family atmosphere that has great influence on the development of the child with ASD is the economic situation.

A situation of financial strain is capable of causing a high load of stress among family members, especially as regards access to health services for the child with ASD.^{6,12,20,22-3,35}

Like any child with a disability, the child with ASD demands greater professional care, both in the early stages of identification of symptoms and diagnosis of the disorder, as in the phase of treatment.²⁹ Thus, there is a high financial cost related to access to these specialized services, which is further

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aggravated by the high rate of mothers who end up quitting their jobs in order to take care of their child with ASD. 14-15,17,19-20,26

Therefore, in addition to generating stress among family members, a weakened economic situation hinders families' access to services that help the development of a child with ASD. 14-15,17,19-20,26

CONCLUSION

There were few studies describing the direct influence of the family in the development of the child with ASD, mainly in Brazil.

Various situations that occur in the family environment have the ability to influence positively or negatively the child's development. The parental style stood out as the most studied variable. The culture, the parental alliance and the economic situation also have great interference in the child's development.

These variables may change over time and according to the family needs from professional and social aid.

Therefore, the present study provided important subsidies for understanding intrafamily situations that influence the development of children with ASD. Moreover, this study may contribute to the emergence of new studies related to the topic mainly at national level.

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