

Experiences of families with autistic children: an integrative literature review**As experiências de famílias com filhos autistas: uma revisão integrativa da literatura****Las experiencias de familias con hijos autistas: revisión integrativa de la literatura**

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Abstract: An integrative review of the national and international scientific literature on autism and families analyzed 91 published articles between 2013 and 2020. There was a prevalence of international, empirical, and quantitative articles on caregivers, with an emphasis on experiences that lead to higher levels of stress, depression and overload of work in the family. The content analysis of the articles showed four categories: experiences, challenges and maintenance of family relationships ($n= 38$); resources and strategies to face these challenges ($n= 29$); fraternal subsystem ($n= 10$); and social support network ($n= 14$). The results are valid for research and studies focused on families with autistic children from little studied perspectives that include positive and strengthening aspects in the face of the adversities experienced.

Key Words: Autism, ASD, family, family relationships, resilience

Resumo: Uma revisão integrativa da literatura científica nacional e internacional sobre autismo e família analisou 91 artigos publicados entre 2013 e 2020. Prevaleceram artigos internacionais, empíricos, com delineamento qualitativo, realizados com cuidadores, com foco em experiências que levam a altos níveis de estresse, depressão e sobrecarga familiar. A análise de conteúdo dos artigos gerou quatro categorias: vivências, desafios e manutenção das relações familiares ($n= 38$); recursos e estratégias para enfrentar os desafios ($n= 29$); subsistema fraterno ($n= 10$); e rede de apoio social ($n= 14$). Os resultados são úteis para pensar pesquisas e trabalhos voltados para famílias com crianças autistas a partir de perspectivas ainda pouco estudadas e que incluem seus aspectos positivos e fortalecedores na leitura das adversidades vivenciadas.

Palavras-chave: Autismo, TEA, Família, relações familiares, resiliência



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Resumen: Además del conocimiento técnico, la actuación profesional requiere competencias personales y sociales. El presente trabajo tuvo como objetivo comparar el repertorio de habilidades sociales de los estudiantes de inicio y fin de los cursos de Psicología y Enfermería de una institución pública brasileña. Ciento treinta y nueve estudiantes universitarios respondieron a un cuestionario inicial y al inventario de Habilidades Sociales - IHS-Del-Prette. Los resultados indicaron correlaciones entre tiempo de curso y cantidad de actividades académicas clase extra y habilidades sociales específicas. Los estudiantes de Enfermería presentaron puntajes mayores en habilidades sociales que los de Psicología. Los estudiantes que participaban en actividades académicas clase extra, aquellos que ya habían ingresado en otros cursos y las mujeres también presentaron puntajes mayores en factores específicos. Se concluye que experiencias como actividades prácticas de los currículos de los cursos, ingreso en otros cursos y la participación en actividades académicas clase extra, además de roles de género, pueden afectar el desarrollo de las habilidades sociales.

Palabras clave: habilidades sociales, estudiantes universitarios, Enfermería, Psicología

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In 1943, the Austrian physician Leo Kanner (1894-1981) published the article “Autistic disorders of affective contact”, in which he reports on the cases of eleven children followed up at John Hopkins Hospital (United States) who had a number of characteristics in common. Kanner describes these as a syndrome, then called Early Childhood Autism, whose main feature lies in the difficulty in establishing relationships with people and situations (Tuchman & Rapin, 2009).

Around the 70s, longitudinal studies based on home movies with babies brought new concepts about the psychogenesis of autism (Brasil, 2015). As of 2013, with the launch of the DSM-5 (American Psychological Association [APA], 2013), the syndrome came to be called Autism Spectrum Disorders (ASD), with the following diagnostic criteria: difficulties in communication and social interaction, repetitive and stereotyped behaviors, and restricted and narrow interest in the surrounding environment. There is an onset in early childhood, but in some cases the most striking features may appear late, making it difficult to start interventions early.

Due to the specificities of its development, since 2012, with Law 12.764 / 12, which institutes the National Policy for the Protection of the Rights for the Person with Autism Spectrum Disorder, in Brazil, the autistic person is considered a person with a disability so that he / she has access to guidelines that address care actions and policies, participation in the community, comprehensive attention to health needs, insertion into the labor market and other rights, such as

inclusion in the regular education system. However, controversial views encourage us to think about new possibilities for the understanding of the autistic person beyond the diagnosis based on nosographic characteristics. Based on this bias, therefore, autism is neither conceived as a disease (genetic or psychic) nor as a disability, but rather as a form of “singular subjective functioning” (Maleval, 2017).

Studies that address different aspects of family and autistic child interaction show that the levels of anxiety and stress in these families, especially in caregivers, may be higher as a result of the diagnosis (often given inconsistently and unclearly), of the atypical development of these children, lack of communication, behaviors that are difficult to manage, and little social and family support (Samadi, McConkey, & Bunting, 2014).

The results of surveys show that the family needs greater support in regard to the couple and the other children to overcome difficulties. Thus, it is essential to view the family as a field of intervention to strengthen family bonds, expand the support network and facilitate the therapeutic processes around the person with autism. Based on these considerations, this article aimed to carry out an integrative literature review on the theme of autism and the family, aiming to analyze the existing national and international scientific production on the theme in the period from 2013 to 2020.

Methods

This is an integrative literature review, which aims to gather and synthesize research results on a given subject or theme, in a synthesized and orderly manner (Mendes, Silveira, & Galvão, 2008).

Data Collection: data were searched in databases Scielo, PePsic, Indexpsi, Lilacs, PubMed and PsycInfo based on the descriptors: autism (OR) autism spectrum disorder (OR) ASD (AND) family (OR) relationships, in Portuguese, Spanish and English. The period from 2013 to 2020 was delimited to cover research and studies that presented broad and varied views on autism, when it became part of the picture of Autism Spectrum Disorders from the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM).

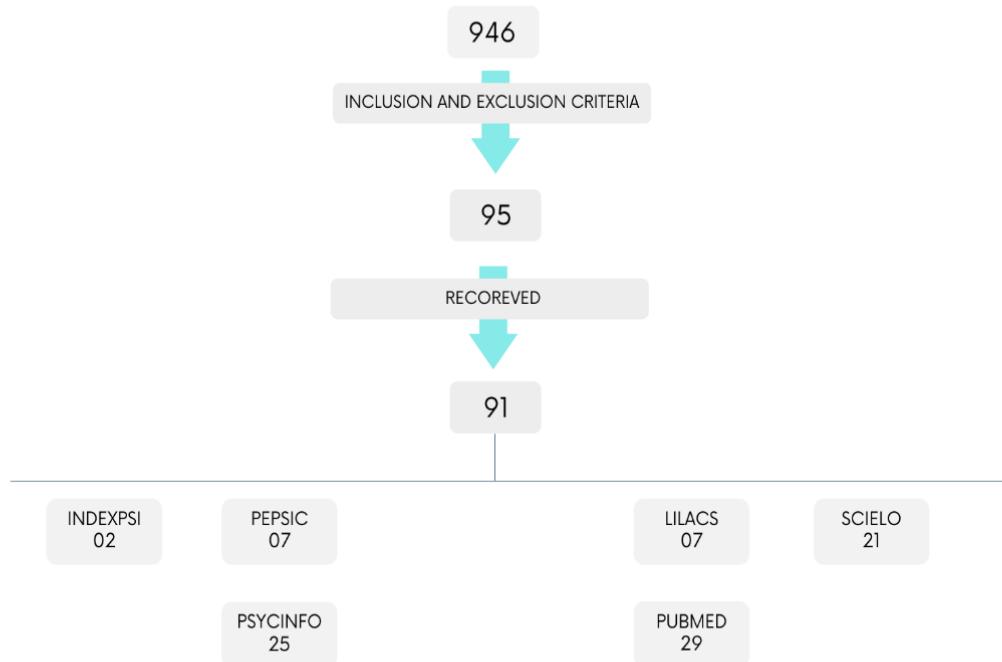
The selected sample included complete articles indexed in journals using the following inclusion criteria: articles reviewed by peers; relevance to the theme, with emphasis on the main aspects related to families of autistic people; and published between 2013 and 2020. The exclusion criteria were: studies that were aimed exclusively at people with autism over the age of eighteen; those that did not directly address family relationships and experiences; and repeated articles.

Data analysis: for the synthesis and interpretation of the results, two analyzes were performed. The first used a quantitative design, including the identification of the following dimensions of analysis: database, title, year of publication, author(s), country, summary, design (quantitative/qualitative/multi-methods), type of study (empirical, theoretical), profile of participants and categories found. The second analysis, with a qualitative design, used Content Analysis procedures (Bardin, 2016) and originated four thematic categories and their subcategories, elaborated from the frequency of the themes in the studies.

Results and discussion

The first search registered 946 articles. After applying the inclusion and exclusion criteria, a total of 95 articles were found, of which 91 were recovered, totaling 95.78% of the sample, distributed as follows: Indexpsi (2), PePsic (7), Lilacs (7), Scielo (21), PsycInfo (25) and PubMed (29) (Figure 1).

Figure 1.
Scheme of Article recovery



Quantitative analysis of scientific productions

The studies were divided into two samples, one was more general, covering national and international studies, and another was national, with studies published in Brazil (See Table 1). Based on data obtained from the general analysis of the studies, most articles were written in English ($n= 60$), followed by Portuguese ($n= 28$). As for the period of publications, the year 2015 had the largest number, with 22 articles, followed by 2014 ($n= 20$), 2016 ($n= 18$), 2019 ($n= 9$) and 2013 ($n= 8$).

Table 1
Quantitative characterization of retrieved studies (n= 91)

Quantitative Categories	Sample (General)	Sample (Brazil)
Year	2013 (n= 8) 2014 (n= 20) 2015 (n= 22) 2016 (n= 18) 2017 (n= 5) 2018 (n= 6) 2019 (n= 9) 2020 (n= 3)	2013 (n= 1) 2014 (n= 6) 2015 (n= 5) 2016 (n= 3) 2017 (n= 3) 2018 (n= 5) 2019 (n= 4) 2020 (n= 3)
Nationality of the first author / States in Brazil	India, Iran, Ireland, Israel, Jordan, Malaysia, Peru e Singapore (n= 1) Argentina (n= 1) Portugal (n= 1) Spain (n= 1) South Africa (n= 3) Australia and China (n= 3) United Kingdom (n= 6) Canada (n= 7) Brazil (n= 29) USA (n= 29)	Paraíba, Roraima, Goiás (n= 1) Santa Catarina (n= 2) Sergipe (n= 2) Bahia (n= 2) Espírito Santo (n= 2) Minas Gerais (n= 2) Rio Grande do Sul (n= 5) São Paulo (n= 11)
Type of Study	Empirical (n= 74) Theoretical (n= 17)	Empirical (n= 24) Theoretical (n= 5)
Method	Quantitative (n= 34) Qualitative (n= 36) Multi-methods (n= 4)	Quantitative (n= 6) Qualitative (n= 16) Multi-methods (n= 2)
Sample participants	Families/caregivers (n= 37), Mothers (n= 17), Fathers (n= 1), Parental couple (n= 12), Siblings (n= 7)	Families/caregivers (n= 10) Mothers (n= 5) Parental couple (n= 6) Siblings (n= 3)
Instruments	Interview (n= 26) Questionnaire (n= 8) Scale (n= 8) Interview/questionnaire (n= 7) Scale/questionnaire (n= 22) Scale/questionnaire/interview (n= 1) Case study (n= 2)	Interview (n= 12) Questionnaire (n= 2) Scale (n= 1) Interview/questionnaire (n= 6) Scale/questionnaire(n= 3)

The largest index of publications is grouped in North America, between the United States of America and Canada ($n= 35$), followed by Brazil ($n= 29$), in which there is a concentration of studies in the South and Southeast regions ($n= 16$). The prevalence of research in the United States is partly due to the movement that emerged in the mid-60s, guided by family members of people with autism in search of better conditions for therapeutic interventions and the inclusion of all autistic children in the public education network (Donvan & Zucker, 2017). Leo Kanner himself, the first doctor to name and include autism within a nosographic category, emigrated to North America, thus enabling the beginnings of studies and research aimed at understanding the phenomenon and its possible clinical and therapeutic implications.

The USA is also the scene of divergences between different psychological approaches, among which psychodynamic and behavioral theories stand out. This fact, far from being just another impediment, provides incentives for research and experimental studies, as well as dialogue between different human, social and biomedical sciences, in the frantic search for answers to the unknowns imposed by the portrait of autism. In Brazil, the decline observed in the publication of studies demonstrates the worrying reduction of government investments in promoting research in a generalized way (Moura & Camargo Junior, 2017), reflecting the political and economic crisis experienced in the country, which worsened in the past decade.

There is also a prevalence of empirical studies ($n= 74$), followed by qualitative ($n= 36$) and quantitative ($n= 34$) designs, while Brazil continues with more qualitative studies ($n= 16$). As for the instruments, interviews, scales and questionnaires were used widely, separately or jointly, with only two case studies. The importance of case studies is highlighted, as these can vary from an individual to a community, and are an important tool for understanding family dynamics and the meanings of phenomena experienced by the whole family as a functional unit or by individual members (Dessen, Silva, & Dessen, 2011).

The samples of participants varied between families / caregivers ($n= 37$), single mothers ($n= 17$), parental couples ($n= 12$) and siblings ($n= 7$). There is only one study conducted with just fathers, which draws attention to the important gaps in research with families since the father figure is also an important part of the subsystems in which the autistic child participates (Shave & Lashewicz, 2016). However, it is interesting to investigate the parents' willingness to participate in the studies, whether due to external factors, such as time, or the absence of a desire to contribute to the research, or because they perceive or are perceived as someone whose narrative does not contribute to the investigations in the field of autism, since women are the central figure of care recognized in all studies investigated in this review. It is also important to clarify that in the sample of family members / caregivers, not all researches clearly specify whether they are both the child's actual parents, only one of them, or other family members responsible for the care.

Qualitative analysis of scientific productions

The qualitative analysis highlighted the following thematic categories: 1) Experiences, challenges and maintenance of family relationships ($n= 38$); 2) Resources and strategies to face these challenges ($n= 29$); 3) Fraternal subsystem ($n= 10$); and 4) Social support network ($n= 14$).

1) Experiences, challenges and maintenance of family relationships

The family of a child diagnosed with autism can experience dramatic changes in social life, expectations, family plans, professional life, financial status and emotional well-being (Fadda & Cury, 2019; Machado, Londero, & Pereira, 2018; O'Connell, O'Halloran, & Doody, 2013). The moment of disclosure of the diagnosis impacts on previous expectations, dreams and life projects, and can be marked by a phase of imbalance. Sometimes it takes a long time for the family to regain stability and start the coping process (Alli, Abdoola, & Mupawose, 2015). Generally, when receiving the diagnosis, family members feel unclear about what autism represents, about the

possible forms of treatment and the possibilities of prognosis, which intensifies these feelings. In addition, family dynamics and individual contingencies will determine the manner and time of the elaboration of this period of adjustment, in addition to the necessary reactions in face of this, such as redefinition of roles, acceptance of the diagnosis and constitution of family dynamics.

The establishment of a bond between the child, the family and the health professionals who accompany the diagnostic process is important at this moment, as it reflects positively on the way in which family members deal with and face the problem (Pinto et al., 2016). The professionals' understanding of how the family interacts with the new situation allows for the perception that caregivers also need care and guidance in the development of strategies for stress relief and other difficulties (Misquiatti, Brito, Ferreira, & Assumpção Junior, 2015). In regard to this, it is important to have a deep awareness and understanding, going beyond theory to work more effectively with families, enabling the identification of a crisis and the understanding that normal life events can increase and intensify stress at any time (O'Connell et al., 2013). Professionals need a more proactive role in perceiving what is said and not said by the family, involving parents and recognizing their strengths, limitations and concerns and enabling their continued growth. Furthermore, it is not possible to work with the autistic child in isolation from their family, nor can parents and family members be seen only as a means of providing support and care (Alli et al., 2015).

In comparative studies of families of children with different developmental issues (autism, cerebral palsy, Down syndrome), it is observed that a negative view predominates, with feelings and reactions of rejection, sadness, prejudice, dependence and overprotection. Families that have a positive outlook are able to highlight their children's abilities, presenting common regularities as potentializing characteristics.

The low perceptiveness of the subjects' potentialities may be related to the negative characteristics overshadowing the positive ones, with the need for a clinical practice that is open to the demands and expectations of the families, with sensitive listening and understanding of the place that this child occupies in the family context. However, it is also possible that, when working with possible prognoses in communicating the diagnosis, health professionals end up influencing the parents' perception of the child when they underestimate or undervalue the potential or disabilities of the child, who is in full development and has a range of possibilities in front of them, even with some limitations, whether physical, psychological, neurological or attitudinal (Givigi et al., 2015).

After the diagnosis phase, the family will face new demands at each stage of development, many of which are similar to those that families of children with typical development have (Minatel & Matsukura, 2014). In studies with autistic children and adolescents, it is pointed out that the daily lives of all the families revolve around their children and adolescents with autism, their needs and difficulties, both in the home and in the social context. Some difficulties in daily tasks are common to all age groups, such as social activities and tantrums and idiosyncrasies, while others are specific to the stage of development in which the subject is at. In children up to 12 years of age, for example, more difficulties are found related to acceptance of the diagnosis, communication, behavior, too much attention and prejudice arising from the social environment. In adolescence, parents report greater difficulties in relation to their child's dependence, hygiene and activities involving touch and physical contact, challenging behavior, tantrums, self-harm, socialization with peers and the development of sexuality (Segeren & Françozo, 2014).

It is natural that parents are more present in the care routine of young children, but as they grow up and gain autonomy, they start to perform many of these activities on their own. However, the more advanced the age of the child or adolescent, the more tired the parents get, especially if they still need to be very present in everyday activities (Bagatell, Cram, Alvarez, & Loehle, 2014). Although there are reports of caregivers who do not face difficulties with the routine, all these

facts bring concerns to the family about the child's future, especially with their absence after death (Segeren & Françozo, 2014).

Despite the necessary adaptation in the roles of the members of the family and the mobilization to divide the activities, the maternal figure is usually in charge of care, and this fact can be understood from historical and cultural representations of gender roles, from what is attributed to woman and which is still supported by traditionally patriarchal cultures. In addition to her full dedication to her autistic child, she still needs to divide herself between her other children, the marital relationship and household chores - roles whose performance may be impaired.

It is necessary that this discrepancy between roles is problematized. Mapelli et al. (2018) point out, for example, that while the figure of the mother reflects the need for care and acceptance of the child, it is up to the father to support and provide the home, which distances him from the therapeutic follow-up and gradual acceptance of the diagnosis. In an important study that investigates the impact of single parenting on the mental health of mothers who care for autistic children, Ferreira and Smeha (2018) found similarities in the experiences of single and married mothers in the daily care of their children, however, the most important point that differentiates them may be in the intensity with which this care needs to be exercised in the absence of a partner who assists them in the division of parental tasks. Therefore, it is reinforced that the inclusion of the father in routine consultations with health professionals can bring great contributions to the flexibility of family dynamics, in addition, in the absence of a more immediate support network, professionals can exercise important support for the mothers.

In comparative studies of families with children with autism and families with children with other disabilities (Samadi et al., 2014), mothers with autistic children obtain results similar to mothers of other groups in coping with stressors related to work, finances, grief, health, and family and social relationships. It is noted that these are events generally external to the family, and not directly related to the autistic child, as pointed out by studies (Dardas & Ahmad, 2014) that consider the autistic child as a significant source of stress for parents due to severity and chronicity of autism and the child's behavioral particularities that interfere in their development and learning.

Research shows that family characteristics of ethnicity, housing, level of education of caregivers and level of religiousness (Mira, Berenguer, Baixaúli, Rosellí, & Miranda, 2019; Schertz, Karmi-Visel, Tamir, Genizi, & Roth, 2016), have a significant impact on families' quality of life. In addition, there is the influence of important transformations that occur throughout the family's life cycle, such as the transition to adulthood, a period in which there may be less frequency of challenging behaviors, less support needs and greater strength of the parents' religious faith. (Boehm, Carter, & Taylor, 2015).

It was also found that high scores of anxiety and depression (Kuhlthau et al., 2014) are related to low quality of life, in such a way that the impact of tiredness, exhaustion and pressure caring for a child not only limits psychological aspects but also quality of life, economic status and family relationships. In addition, the intensity of time used to care for children with autism influences the quality of relationships with other family members, which can result in difficulties in the relationship between other family subsystems, such as increased conflicts between spouses, resulting in lower marital satisfaction (Samadi et al., 2014). In addition to these difficulties, the family can still face prejudice and a lack of support from the extended family and the community, with their consequent departure from social life (Zanatta, Menegazzo, Guimarães, Ferraz, & Motta, 2014).

Mothers are also more likely than fathers to feel harmed by the negative emotional, social, physical and psychological impacts associated with their child's autism, since the constant attention that some children demand requires that mothers pay constant attention to the child and, therefore, they may have less time to meet their own health needs (Constantinidis, Silva, & Ribeiro,

2018; Dardas & Ahmad, 2014; Pereira, Fernandes, & Relva, 2018). On the other hand, greater social support and higher family income can predict better quality of life for mothers of children with ASD, perhaps because these families have the opportunity of more access to resources to deal with stress.

These losses are also reduced when the child has better cognitive development and can more adequately express themselves through the use of verbal language. For example, Balestro and Fernandes (2019) point out that the child's level of communication is directly related to the parents' perception of their child's development and skills. Along with speech therapy interventions that improve the communicational aspects, there is a significant increase in the interaction between parents and child and synchronicity in language. It should be noted that better communication in the family contributes to reducing the stress associated with the absence of communicative expression, verbal or non-verbal, where parents can better interact with their children and feel connected to them.

Other factors contribute to raising stress levels, such as parents' emotional health; parent gender; child's behavioral problems; existence of other dependents at home; quantity and quality of informal support (Samadi et al., 2014); stigmas; lack of adequate services and high financial costs; rejection of the child by peers, family and wider community; lack of adequate information and qualified professionals; and parents' difficulty in engaging in other professional activities or family responsibilities that do not refer to the care of children with autism (e.g. Athari, Ghaedi, & Mohd Kosnin, 2013; Gona et al., 2016). For this, social support helps in coping strategies and can positively influence the perception of burden on the part of caregivers (Samadi & McConkey, 2014). In this regard, the contribution of Fernandes, Speranza, Mazak, Gasparini, and Cid (2020) stands out, pointing to the possible impact of unexpected events, such as the Covid-19 pandemic, on the routine and mental health of children and adolescents with diagnosis of autism and their families, and the extent to which the support and guidance of health and education professionals, the collective and the community can be essential for reducing stress and facing challenges.

In order to adapt to the new routine of care and attention to the child, the main caregiver, when performing a work activity outside the home environment, often needs to give up their professional life to dedicate themselves fully to the child. This transition process is fraught with stress, as parents decide which of the two will abandon their career to take on the role of primary caregiver, with the spouse with the highest financial income becoming the main wage earner, while the other gives up his or her professional life (Constantinidis et al., 2018; Stoner & Stoner, 2016). In some families, however, this decision already seems to have been made since the discovery of the diagnosis, being naturalized on a daily basis and reinforced by the role of women in society, having been chosen, without much choice, to exercise this new role and give up a professional career, a fact that is aggravated by the accumulation of roles and responsibilities due to the excessive demand of time for care that the child needs (e.g. Kwok, Leung, & Wong, 2014; Misquatti et al., 2015; Tabaquim, Vieira, Razera, & Ciasca, 2015; Zanatta et al., 2014).

Caregivers hope to continue their careers in the future, when the child is older, but for some, this possibility seems remote and unlikely. The impact of this loss results in other losses that are not only financial, with reduced purchasing power for the family, economic difficulties (Saunders et al., 2015) and greater work burden and pressure for the working spouse, but also emotional, with feelings of loss and grief, isolation and lack of appreciation for the spouse who becomes a caregiver. The presence of an active professional life tends to play a protective role, as it helps to redirect interests and responsibilities, and, despite the time spent at work, makes caregivers more emotionally available, providing a more pleasant relationship with the child, a factor which influences the way they visualize their self-efficacy while occupying the role of caregivers (Tabaquim et al., 2015).

2) Resources and strategies to face the challenges

Families develop several coping strategies, which can be focused on emotion or the problem (Antoniazzi et al., 1998). In this literature review, many studies were found that report on the use of strategies focused on the problem, which indicates that, possibly, families are well assisted and manage to develop positive adaptation in the face of the challenges faced.

The strategies focused on emotion allow for the reduction of discomfort related to stress, but they do not have a prolonged effect because they represent situational and palliative actions, such as the use of physical punishment, for example hitting, restraining, and locking rooms or bedrooms as a way to correct the child's behaviors that trigger stress processes in parents (e.g. Mine et al., 2015; Tilahun et al., 2016); and not telling the child and/or not talking about their diagnosis (Finnegan, Trimble, & Egan, 2014) in an attempt to ignore the problem and try to lead a "normal" family life.

In turn, *strategies focused on the problem*, such as the parents' difficulty in dealing with and managing the child's behavioral problems, alter the situation in the relationship between the person and the environment that triggers the tension (Antoniazzi, Dell'Aglio & Bandeira, 1998). As examples the studies point out: sharing with health professionals and family members about the diagnosis, fears, doubts and difficult management situations (Aguiar & Pondé, 2020; Tilahun et al., 2016); participating in intervention and support programs or groups for parents and family members (Tellegen & Sanders, 2014); comparing personal experiences with those experienced by other parents (Huang & Zhou, 2016); as well as good humor (Rieger & McGrail, 2013). Coparenting, the process by which parents support each other and coordinate the responsibilities of child care, is also cited as an important strategy, acting as a mediator of the relationship between challenging behaviors of the child and the parents' stress level, so that parents of children with a higher number of atypical behaviors and who work together in child care report less stress (Yes, Cordier, Vaz, Netto, & Falkmer, 2015).

Parker, Diamond, and Auwood (2019) are important references for brief therapy with a focus on solutions, aimed at fathers and mothers as a coping strategy to manage common situations in the context of disabilities and delays in the development of their children. However, the authors recommend that each therapy be built in a unique and individualized way, according to the difficulties and needs of each family. This aspect is important, as each family has its own functioning dynamics and has its own tools and resources for handling adversity, so that the interventions reach the strengths and potentialities of these families in their unique universe, although sharing experiences with other families experiencing similar situations is also beneficial.

The important role of beliefs is also highlighted, as these are symbolic representations that configure expectations, desires, motivations, conflicts, feelings and aspirations, influencing decisions and emotional responses. Beliefs help to organize the lived experience, allowing family members to build meaning from crisis situations (Semensato & Bosa, 2014), and are associated with the adaptation of caregivers (Meimes, Saldanha, & Bosa, 2015) because they can provide comfort, minimize their anguish and facilitate adaptation to the child's side.

Religious and spiritual beliefs help to reduce the negative consequences of the phenomenon and provide learning through pain and troubles (Cloete & Obaigwa, 2019; Minhas et al., 2015; Tilahun et al., 2016). Despite the various beliefs, it is important to have realistic expectations regarding the child and to maintain a quality family atmosphere, these being two fundamental aspects in the positive coexistence of the family to avoid possible complications at the individual, family and social level (Palomino-Moore, Vargas-Leo, & Vaiz-Bonifaz, 2014). It is possible that the expectation of a cure facilitates the parents' engagement in the treatment of their child, but not many studies have been identified on belief in healing that could support this hypothesis or serve as a basis for comparison between families with autistic children in the context of religious cultures.

In addition, cultural influences, education levels and socioeconomic conditions also contribute to the formation of parental beliefs about autism (e.g. Minhas et al., 2015; Zuckerman, Lindly, Sinche, & Nicolaidis, 2015). Parents with higher levels of education are more likely to have beliefs about the child's developmental difficulties being mitigated by therapeutic possibilities, although they understand autism as a lifelong condition, which enables them to search for accompanying treatment. Beliefs related to the efficacy of treatments in promoting changes in the child may be consistent with the thought that autism is a part of, or is the very identity of the child, and therefore not something that the family finds necessary to change (Zuckerman et al., 2015).

There is an emphasis on the adaptive aspects that can be found in these families, so that the presence of a member with autism in the family does not necessarily represent adversity for the family. To this end, the positive influences of the social support network, intra- and extra-family resources, and the strategies used to manage difficult situations are affected. When family expectations for themselves and their children begin to change, becoming more attainable, they begin to show a sense of gratitude and hope for the future. Hope is also associated with greater family support, which in turn is associated with reduced feelings of loneliness and lower symptoms of depression (Ekas, Pruitt, & McKay, 2016).

In contrast to studies that present the negative aspects of living with autism, research shows that many parents achieve positive adaptation by having a child with a disability, considering this as an experience of growth and learning of humility, patience, compassion, acceptance and respect (Meimes et al., 2015; Reddy, Fewster, & Gurayah, 2019; Semensato & Bosa, 2017). In addition to the difficulties, there is a positive belief about the development of children and, although it is difficult to live together at times, autism is a reason for strengthening family bonds, leading family members to gain a deep sense of meaning, purpose and personal growth (Dykens, 2015).

It appears that some of the negative generalizations and overwhelming experiences of families with children diagnosed with autism are no longer supported by current research. An emerging area is resilience research, which focuses on identifying positive characteristics of individuals and encouraging their coping skills by developing strategies that allow them to deal with stress and adversity (Rieger & McGrail, 2013). This model has also been one of the main theoretical frameworks adopted to work with families facing crises or stressors, and in this context it is understood as family resilience and its basic premise is that persistent crises and challenges have an impact on the family as a family unit.

The resilience model involves a combination of risk and protective factors. Risk factors are those that increase the likelihood that an adverse event will compromise the positive development of individuals, while the protective factors act as protective shields against these challenges, and include family belief systems and coping strategies previously mentioned in that review. According to Whitehead, Dorstyn, and Ward (2015), both factors can fluctuate over time, and the same factor can confer protection or risk depending on the context being experienced. For the authors, resilience is associated with the sum of protective factors with the activation of the social and community support network (family and non-family), which provides emotional and instrumental support for families to deal with stressful situations. Resilience is still understood as a dynamic and systemic process, justifying the importance of involving all family members (Dykens, 2015; Foo, Yap, & Sung, 2014; Rieger & McGrail, 2013; Semensato & Bosa, 2017).

3) Fraternal Subsystem

In the fraternal subsystem there are socializing aspects towards which the most diverse ambivalent feelings are directed, such as embarrassment from the sibling, companionship associated with the family, willingness to take care of the sibling and help the parents, as well as worry and anguish. The relationship between siblings can be facilitated by friendships in common, by the relative autonomy of the autistic sibling, by the family and specialized support networks,

and by the guidance on the part of families in regard to siblings with autism, considering their difficulties and limitations (Loureto & Moreno, 2016).

In some cases, the autistic sibling starts to be seen more as a son or daughter, regardless of whether s/he is younger or older, and this role reversal may occur due to the family's need to adapt to the new situation, so it is common for siblings to help parents with their daily tasks during all phases of the family cycle, seeking to ease the overload of tasks, especially the mother's, as they carry greater responsibility, causing instability in their level of stress and emotional balance. (Mandleco & Webb, 2015; Vieira & Fernandes, 2013). This role reversal is also called *parentification*, and it can occur in families where there are members with disabilities, resulting in positive and negative aspects depending on the family context (Tomeny, Barry, Fair, & Riley, 2017).

Parental satisfaction is a predictor of adjustment among neurotypical siblings (Hesse, Danko, & Budd, 2013), relating to the fact that, when they feel more satisfied with the care of a child with autism, parents start to see the adaptation of the siblings as positive, as a reflection of their own adaptation. However, not all siblings are satisfied with the amount of time and parenting styles taken up by the caregivers, especially when they are unable to equally divide the attention between the siblings, and may feel neglected or less important compared to the diagnosed sibling (Cezar & Smeha, 2016).

Family individuality, coping strategies, social support and assistance received directly influence the perception of quality of life of siblings of autistic children (Vieira & Fernandes, 2013). Therefore, it is important to have interventions with the siblings, in order to help them understand the behavioral problems present in the condition of autism, contributing to the reduction of depressive symptoms and improving the relationship in the fraternal subsystem (Lovell & Wethrell, 2016). Mental health services usually focus only on children with autism, so the work with siblings is rarely brought into the discussion (Chan & Lai, 2016). It is important that parents and professionals are attuned to the needs of other children.

The siblings also experience positive aspects and experiences in having a sibling with ASD, such as: the development of positive personality characteristics, with higher levels of empathy and patience; greater awareness of recognizing when your siblings are sad, frightened and frustrated, which leads to higher levels of understanding and empathic behavior; and feelings of pride and appreciation towards their brother or sister (Shivers & Plavnick, 2015; Turns, Eddy, & Jordan, 2016).

4) Social Support Network

A social support network is essential to assist parents in developing effective strategies for coping with adversity. This network can be family and non-family, and includes friends, neighbors, religious groups, school, community, network of parents, health team and public policies that support family assistance programs. After the diagnosis has been made, the health team, in particular, can provide parents with a form of informative counseling, showing them the possibilities and limits to be expected and faced, teaching them ways to interact with the child and how they can help develop skills through games and play (Clifford & Minnes, 2013; Corrêa & Queiroz, 2017; Cossio, Pereira, & Rodriguez, 2017).

As an example of support programs aimed at parents and families of children with autism, we can mention the creation of an online blog as a strategy to reduce maternal stress and improve the quality of the mother-child relationship (Whitney & Smith, 2014). This practice works as a distributor of stress, so that writing can improve emotional adaptation when a person is faced with stressful life events and can produce significant improvements in psychological well-being. People who express their feelings in some way are better able to deal with stressors, live a healthier lifestyle and are better able to understand themselves and the events of life, which also provides significant improvements in health. Virtual tools favor the construction of a collective identity

uniting groups of parents from different places, with different beliefs, life histories, and socioeconomic conditions, favoring the experiences they share in common with people with autism, in addition to strengthening the group in the struggle to guarantee rights and other important achievements for their families (Machado & Ansara, 2014).

Support groups focused on siblings (Kryzak, Cengher, Feeley, Fienup, & Jones, 2014) can provide significant improvements in positive adaptation, building a network of peers, increasing knowledge about autism and improving interaction in the fraternal subsystem. One of the expected long-term benefits is that the bonds built within support groups continue to occur even outside.

Although mothers are central figures in care and therefore show more adherence to support groups, it is important that fathers also share their experience with parenting autistic children (Bianchi & Jurado, 2019; Portes & Vieira, 2020; Shave & Lashewicz, 2016;). Fathers exercise parenting better as they manage their child's care needs and understand their role and the type of support they can provide. Although many fathers consider that their role has traditionally been to provide the family economically, they understand that spending quality time with their children is also something very important, not only to have daily contact, but also as a way of working in partnership with their wives, ensuring not only that the child's needs are met, but that each spouse has time available to meet their own individual needs.

Through multi-contextual considerations, Shave and Lashewicz (2016) criticize structures and practices centered only on the figure of the mother. They make recommendations to increase the quality of support for parents and suggest recreational activities where they can get involved with other parents of children with ASD and their children. This can be an opportune moment to recognize struggles, share experiences, and guide younger parents through the experience of having a child with autism. At the same time, parents emphasize the difficulties of participating in such activities as they have to balance time with demands for work, child care and rest.

Houser, McCarthy, Lawer and Mandell (2014) argue that community contexts, where neighbors, religious groups and leisure spaces are included, appear as important aspects that intervene with professional and family commitments. Families can perceive difficulties in obtaining formal and non-formal support, because they feel isolated and affected by stigmas, or because there are few spaces of integrated care for autism, as well as the difficulty of accessing these places. Furthermore, parents spend much of their time and energy on caring for their children, which can reduce opportunities to strengthen the nearest social network. Although parents find caregivers within the family network with whom they can share the burden of care, they are also satisfied when this help comes from someone who does not belong to the family group, however, the difficulty in finding good caregivers is an obstacle faced at the community level by unemployed parents who cannot afford services (Houser et al., 2014).

In addition to the above, it is important that the support network is also supported by effective public policies (Machado & Ansara, 2014) that facilitate the accessibility of families to all available resources to face difficult situations, reducing their emotional, social, physical and financial burdens.

Moreover, the support of teams of professionals based on theories and techniques in the area of health and education, going beyond the moment of diagnosis to the monitoring of people with autism during a large part of the life cycle, the support of the community, family, neighbors and friends is also important for the better health of fathers and mothers of children with autism. Both forms of support have direct effects on the development of children and on the parents' quality of life, since child care that is more effective and of high quality has an impact on children's development and, consequently, on better levels of mental health of parents (Hsiao, 2016). The social support network is part of the social context in which the family develops and thus provides support so that the family can find external resources to face the difficulties experienced, such as security, health, housing, and employment. This network must be based on family-centered

policies, enabling the family to prosper and find different ways of responding to the crisis and the challenge.

Final considerations

This study aimed to carry out an integrative literature review on the theme of autism and the family, aiming to analyze the existing national and international scientific production on the theme in the period from 2013 to 2020. There was a plurality of subjects addressed in national and international studies, highlighting important themes for the family context of autism, such as the diagnostic process, developmental challenges for the child, experiences of adversity, quality of family relationships, parental beliefs, resources to face difficulties, development of programs for monitoring children and family, and social support network, among others.

It was found that in Brazil research that addresses the relationship between autistic people and their family is under-developed when compared with the volume of studies carried out in other countries. In the general sample, qualitative studies, carried out with family members / caregivers of autistic children, predominated. However, the limited number of studies carried out with parents of children within the spectrum, suggests the relevance of creating new studies that focus on parents, whether investigating the meanings they attribute to having an autistic child, or how they integrate care and other co-responsibility tasks, for example.

It was possible to identify the themes emphasized by research on families with autistic children, either in the Brazilian context or in the international context. The considerable number of studies that analyze the quality of life, the levels of depression, anxiety and stress in caregivers of autistic children comes to our attention, with a much greater focus on the adverse experiences experienced by these families during their life cycle. Such experiences start with the path of the parents in search of answers to the child's developmental questions, the search for treatment centers and multiprofessional accompaniment, the exacerbated exhaustion from the daily tasks, and even the reframing of the diagnosis through the grief process and acceptance. It is important to highlight that the adversities, although sometimes related to the daily life of living with an autistic child, were aggravated by other transversal factors, such as marriage problems, lack of support from family or community, low socioeconomic levels, absence of public policies and multi-professional centers to monitor the child and their family.

Few studies described the traits of growth, learning of empathy and love, strengthened family bonds, and the renewed sense of hope and optimism in families with autistic children. However, even highlighting these aspects, they make little mention of the resilience construct, a dynamic process that involves resources from the whole family to deal with adverse situations. Thus, there is a need for further studies that identify aspects of positive adaptation in the families of autistic children, recognizing effective strategies used by them to reduce the significant impacts of the adversities experienced, such as enabling beliefs, the provision of a strong support network and the inclusion of families in support or therapeutic groups.

It is understood that resilience, when understood within the family context of autism, allows researchers, health and education professionals, and even families, to understand the experiences of adversity as opportunities for strengthening and growth. This vision breaks away from the fatalistic and victimizing conception / practice of these families, and contributes to the reduction of stigmas and prejudices and expands the incentive for the development (in the scientific, political, educational, social and health fields) of interventions aimed at strengthening and growth of families that live daily with autism.

This study contributed to analyze the main aspects related to families of autistic people and enrich the discussions around the theme. Comprehensively, it demonstrated the various issues that encroach on the daily lives of these families, underlining the relevance of multi-contextual

perspectives on the phenomenon. Despite the contributions brought by this review, it is understood that it has some limitations, namely: the search for articles in a restricted period of publications (2013-2020), a small sample of Brazilian studies, and a focus on the initial phase of the cycle of family life (families with young children). It is suggested that future literature reviews extend the period of publication of the articles, in addition to covering studies that focus on the family at different stages of the life cycle, in order to understand how the acceptance and adaptation of family members to autism occurs over time.

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