

AUTISM CLINIC AND RESEARCH: ETHICAL LOOK AT FAMILY SUFFERING¹

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ABSTRACT. In this article, we aim to discuss, from a standpoint of the field of Ethics, some impacts that autism may have on the family. We made a literature review about possible effects of autism on family relationships and autobiographical texts of relatives of people with Autism Spectrum Disorder (ASD). We discuss how people with ASD, with their singularities, may impact family relationships, and how the person's subjectivity simultaneously impacts and is impacted by the family. In this way, we hope to broaden and deepen the horizon of researches that focus on such issues providing new elements for listening and caring for parents and siblings in autism-related treatment.

Keywords: Autism; family; ethics.

CLÍNICA E PESQUISA DO AUTISMO: OLHAR ÉTICO PARA O SOFRIMENTO DA FAMÍLIA

RESUMO. No presente artigo, temos como objetivo discutir, do ponto de vista da ética, alguns impactos que o autismo pode ter nas relações familiares. Para tanto, recorremos a uma revisão bibliográfica acerca de possíveis efeitos do autismo nas relações familiares e também à apresentação de recortes autobiográficos de famílias de crianças com Transtorno do Espectro do Autismo (TEA). A reflexão desenvolvida ao longo do artigo leva a pensar sobre como a criança com TEA, com suas singularidades, pode vir a impactar as relações familiares e sobre como a subjetividade da criança afeta a família ao mesmo tempo em que é afetada por ela. Dessa forma, esperamos alargar e aprofundar o horizonte das pesquisas que enfocam este tema e fornecer novos elementos para a escuta e cuidado dos pais e irmãos na clínica do autismo.

Palavras-chave: Autismo; família; ética.

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CLÍNICA E INVESTIGACIÓN DEL AUTISMO: MIRADA ÉTICA AL SUFRIMIENTO DE LA FAMILIA

RESUMEN. En este artículo, nuestro objetivo es discutir, desde el punto de vista de la ética, algunos impactos que el autismo puede tener en las relaciones familiares. Para habilitar esta discusión, recurrimos a una revisión de la literatura sobre los posibles efectos del autismo en las relaciones familiares y también a la presentación de recortes autobiográficos de familias de niños con Trastorno del Espectro Autista (TEA). La reflexión desarrollada a lo largo del artículo lleva a pensar cómo el niño con TEA, con sus singularidades, puede impactar las relaciones familiares, reflexionando sobre cómo la subjetividad del niño afecta a la familia al mismo tiempo que se ve afectada por ella. De esta manera, esperamos ampliar y profundizar el horizonte de investigación sobre este tema y proporcionar nuevos elementos para la escucha y el cuidado con a los padres y hermanos en la clínica de autismo.

Palabras clave: Autismo; familia; ética.

Introduction

This article aims to discuss the possible autism impacts on family relationships. It is intended to foster this discussion based on two axes: I. A bibliographic review about such effects and II. The presentation and discussion of autobiographical texts of relatives of people with Autism Spectrum Disorder (ASD). We discuss how people with ASD, with their singularities, may impact family relationships, and how the person's subjectivity simultaneously impacts and is impacted by the family. In this way, we hope to broaden and deepen the horizon of the researches that focus on such issues, providing new elements for listening and caring for the whole family of children with ASD.

In the theorization and autism clinic, the caring and listening of parents are essential. Many authors have worked in this perspective, as is the case of Merletti (2018). According to the author, it is part of the autism clinic to care for the parents' suffering. The psychoanalyst points to the importance of "[...] taking care of those who will continue to take care" (Merletti, 2018, p. 146) of children with ASD, from a perspective of encouragement and investing in the role of parents.

Even though this perspective pointed out by Merletti (2018) is shared by psychoanalysts who deal with autism today, and is supported by their studies and enunciated in several formulations, some argue that psychoanalysis still blames parents for their offspring's ASD. The anti-psychoanalytic movement started in the 1980s in France is evidence of the persistence of the stigma mentioned above around psychoanalysis. In 2012, this movement led to many consequences for private and public health, with economic sanctions and an attempt to eliminate psychoanalysis as a form of Autism Spectrum Disorders treatment (Gonçalves, Silva, Menezes, & Tonial, 2017). In Brazil, in September 2012, a public note was launched by the São Paulo Department of Health for the accreditation of mental health institutions working with autism, excluding psychoanalysis as a valid approach. Much of the arguments surrounding this exclusion were related to the idea that psychoanalysis accuses parents of the child's autism, as the official text from the Psychoanalysis, autism and public health movement points out (2020).

Considering this context, the need for psychoanalysts to gather elements to enter this theoretical and scientific debate, specifically in the autism clinic, becomes clear. It is with this aim in mind that, in the present article, we will develop two axes of reflection that will provide clinicians and researchers of autism, psychoanalysts or not, elements to expand their considerations on the subject with an attentive look and listen to the families' suffering.

To situate the issue we are dealing with, we will present, along the following paragraphs, some theories about autism developed mainly by authors of psychoanalysis. We will seek to show how the psychoanalytical perspectives in this field have been broadened since the initial formulations until it became possible to welcomingly support the listening for parents and siblings of children with ASD. We will also seek to demonstrate that over the decades since the nosological category of autism was defined, the conceptions around its etiology and treatment have been changed.

In some early stages of theorization, mothers or caregivers were blamed for the child's autism. Since the 1940s, when psychiatrist Leo Kanner formalized the nosological category of autism, the role of the mother-baby relationship in the genesis of this condition has been the subject of reflections, researches and reformulations. The well-known 'refrigerator mother' hypothesis is emblematic in this sense. Although already refuted, it always calls us to a critical eye and an ethical posture in the studies of children with ASD and their families.

After conducting a study with 11 children who had in common extreme isolation, inability to relate to other people, language problems and obsessive concern for what is immutable, Kanner formulated and defended the idea that the genesis of autism would be the maternal cold stance and both physical and emotional distance towards the baby (Corrêa, 2017). According to this hypothesis, the withdrawal and isolation of the child with ASD would be a defense mechanism in the face of the mother's coldness and lack of genuine love.

This idea led to the formulation of the well-known 'refrigerator mother' hypothesis, which blamed the mother for the child's autism. Donovan and Zucker (2017) remind us that, in 1969, Kanner apologized to an audience of parents of children with ASD for referring to the idea of the refrigerator mother, undoing the misunderstanding that autism would be the parents' fault. Nevertheless, even today, we find ourselves facing blaming perspectives from external critics who, unaware or not referring to current psychoanalytic researches, erroneously claim that this is the current reading of psychoanalysis, which often aggravates the already intense suffering of parents of children with autism.

Although we emphasize that these are outdated theories, we consider them relevant to discuss some of the main lines of argumentation, including because they are repeatedly revisited to criticize the autism psychoanalytic clinic.

In this context, it is worth resuming how the 'refrigerator mother' hypothesis remained present in the thinking and subsequent formulations about the autism etiology. Psychoanalyst Bruno Bettelheim reiterated this idea insofar as he argued that the genesis of autism would be the inefficiency of childcare, an absent father and a frigid and insensitive mother (Bettelheim, 1987). It is worth noting that in 1955 in the book *Fugitivos de la vida* (Bettelheim, 1976), the author recanted this formulation, ceasing to use it.

Subsequent authors of psychoanalysis continued to think about autism etiology, especially from their case studies in its articulation with family interactional dynamics.

Françoise Dolto (Soler & Bernardino, 2012), in the 50s, stressed the importance of working with parents in the field of autism, since to the author, the issues that emerge in early childhood are related to family dynamics. It is possible to see a change from

Bettelheim's initial thinking. If before, parents - and in particular the mother - were seen as guilty for the child's autism, now family issues are still considered in the etiology of autism, but the parents move from the culprit place to be people to be heard and included in the treatment of their children.

Frances Tustin (1984) spoke about the premature separation between the child with ASD and his mother (for example, early interruption of breastfeeding). Since the baby has not undergone completely the process of psychic integration, such a separation would mean losing a part of him. The result would be the defensive reaction of autistic closure for protection purposes. Thus, it is remarkable the consideration of psychogenic factors around autism, especially aspects of the relationship with the mother. It is clear, however, that there is no categorical perspective that blames the mother or caregivers for the child's autism. It is a relational impasse, an early loss suffered by the baby that is not the mother's fault. The early separation could occur, for example, due to the tragedy of the mother's death or due to some external factor that led to the separation of the dyad, associated to the organic vulnerability of the child,

[...] even concerning children in whom psychogenic factors seem to be the most active in the etiology of their psychoses, the cautious psychotherapist cannot rule out the possibility that such children may have minimal neurological damage or lack of metabolic balance that cannot be detected by the currently available physical investigations. Therefore, this is an area where thorough medical knowledge is indispensable (Tustin, 1984, p. 26).

In the mid-70s, Donald Meltzer (1975) addressed the inability of some babies to find a maternal object - whose role may be played by the biological mother or not - capable of containing their helplessness and psychic disorganization. It is essential to highlight that the author mentioned a disability of the babies, and not of the mothers, showing a widening of the perspectives that existed until then, as he mentioned possible difficulties of the baby itself.

Turning away entirely from any parents blaming at the origin of autism, Laznik (2004) increasingly emphasizes that the relational dimension plays a role in this condition, highlighting organic constitutional aspects among babies who would later receive the diagnosis of autism. In this sense, she pointed out difficulties in the baby's regulation of arousal, and the consequence of which would be the defensive avoidance of human contact/closure and the absence of the ability to demand vocally (even in situations of pain and anguish), leading to an experience of helplessness from the part of the baby, given the absence of the possibility of perceiving other people around him as capable of alleviating this intense suffering. More contemporaneously, Burnod and Laznik (2016) stressed the importance of organic issues in the autism genesis that are reflected in the difficulty in the relational bonds and in the possibility of experiencing pleasure in the relationship with other people, highlighting the relevance and potency of therapeutic interventions from an early stage.

From this short path, we see how psychoanalytic studies were not stagnant in Bettelheim's perspectives from the 1940s. Some advances allowed broadening theoretical and clinical perspectives. More and more, we observed the perspective of inclusion of families as allies to treatment.

In this sense, Merletti (2018) points out the importance, in the autism clinic, of welcoming and supporting the process of narcissistic restoration for the parents of children with ASD. They are generally so burdened by feelings of anguish and helplessness and suffered due to the impact of the diagnosis and the challenges they face every day. The

author highlights the relevance of a listening and ethical position that aims to provide elements for listening and caring for the child and his family. It is a perspective of “[...] social co-responsibility of the family in the construction of care, in the symbolic transmission and support of a critical position on the child’s possible places and destinations” (Merletti, 2018, p. 149).

According to Gonçalves et al. (2017), articles with a psychoanalytic approach published between 2009 and 2014 in Brazil which focus on the autism etiology consider multi-causal possibilities for the origin of the disorder, as genetic, biological, relational, environmental and cultural aspects. Thus, the broadening of psychoanalytical considerations that focus on this theme is reiterated.

The brief path through the thinking of these authors makes it evident that those who advocate that psychoanalysis blames parents for the child’s autism are trapped in a discourse that disregards the advances in this field since the mid-20th century until today. As stated, the authors who defended the ‘refrigerator mother’ hypothesis (Kanner and Bettelheim) have already apologized for this. It is worth remembering that Kanner, who first launched this idea, was not a psychoanalyst, but a psychiatrist.

Psychoanalysis contributions

One of the psychoanalysis contributions, in addition to thinking about the autism etiology, refers to listening and welcoming that makes it possible to optimize this clinic, and in this context, we propose that thinking about the impacts of autism on family relationships can contribute to deepen and broaden clinical and research perspectives that focus on this issue.

In the present article, we highlight the relationship between the child and his parents, considering that the son or daughter condition can produce effects on his parents, with a potential influence, in feedback, on the child’s autistic isolation. Simply put, it is as if we are talking about a two-way route relationship. The child has difficulties in establishing social ties; consequently, their parents suffer from such difficulties, with impacts on the parental affective investment, which can worsen the situation of the child with ASD.

The reflection about the family suffering (parents, siblings) of the child with ASD can encourage a broader theoretical-clinical perspective on the impact of autism on the family and which takes into account the power of looking at relational aspects among the child with ASD and their families as a form of care in this clinic. It is not a matter of thinking about agents that cause autism, but considering who is in the children with ASD daily life and who can enhance the proposed interventions and forms of care.

We will take a standpoint of the field of Ethics to discuss the suffering of relatives of children with ASD. At first, we will present studies on the impact of autism on the family (axis 1) and, next, some reflections will be made along with autobiographies written by parents of children with ASD, encouraging exploring ‘a look from inside’ of these families (axis 2).

Method

About the methodology used for writing axes 1 and 2 mentioned above, we carried out: 1. A bibliographic review on possible effects of autism on family relationships in families

of children with Autism Spectrum Disorder (ASD) and 2. Use of psychoanalysis as a reading tool to reflect autobiographical texts written by parents of people with ASD.

Concerning axis 1, we performed a bibliographic review in the Lilacs, Academic Google and Scielo databases with the following descriptors: 'autism impact on the family', 'autism and siblings', 'autism and parents'. The articles selected for reading were all those in the psychology area, excluding those from other areas (speech therapy, biology, medicine). For data analysis, all material was read and summarized using the file resource. Then, the information was organized and selected for writing this article.

Regarding axis 2, we used a vast material with about 100 autobiographies written by people with ASD and/or their parents. Some of these autobiographies were selected to compose the article according to their greater possibility of illustrating the theme of the article.

The autism impact on the family

In many cases of autism, the first symptoms appear early in life. Thus, it is plausible to suppose that these characteristics have an impact on the daily lives of families and the relationships between their members.

In this sense, studies such as that of Schmidt and Bosa (2003) revealed acute stress in families that had a member diagnosed with autism. This perspective allows us to think about how much the uniqueness of the child with ASD can affect the whole family. Thus, we notice a shift from only perceiving the impact of the caregivers' subjectivity (especially the mother's) on the child's psychic constitution, to thinking about how the child affects the family.

In this line of the expansion of studies, it is necessary to think about how autism can affect family relationships and address these relationships and the parents' subjectivity in increasing this clinic. It is in this sense that, in the next few paragraphs, we will reflect on the possible impact of one sibling's autism on the other, as well as on the parents in the search for empathic availability towards these people.

Gold (1993) investigated the differences between siblings of children with ASD and siblings of children with typical development in some aspects such as depression and social adaptation. The author compared 22 siblings of children with ASD with 34 siblings of children with typical development and found higher rates of depression in the first group compared to the second. There was no significant difference between groups concerning social adaptation.

The findings of the impact of having a brother with ASD are not unanimous. In the literature review carried out by Gomes and Bosa (2004), the authors point out that siblings of children with ASD, compared to siblings of children with typical development, tend to assume greater responsibilities and to manifest greater idealism and humanitarian concerns, compared to siblings of children with typical development, suggesting that the impact of autism on the family can take on several facets.

In agreement with the above idea, Rao and Beidel (2009) pointed out that the impacts of having a brother with ASD are controversial and varied. Through a literature review on the subject, on the one hand, the authors indicated studies in which there were no adverse effects of having a brother with ASD and, on the other hand, studies that indicated a higher level of depression, behavioral problems and loneliness in brothers with typical development, attesting that studies on the topic are not yet conclusive.

Rao and Beidel (2009) studied a sample of 30 parents, 15 had children with ASD and 15 with typical development. The results of this study showed higher levels of stress in the group of parents of children with ASD, compared to the control group. According to the authors (Rao & Beidel, 2009), such results call attention to the need for treatment programs aimed at children with ASD are also able to dedicate themselves to the issue of parental stress, which may come to optimize the ownchild treatment. Regarding family functioning, Rao and Beidel (2009) also pointed out a trend, among the parents of the control group, of higher levels of independence (assertiveness, self-sufficiency and ability to make their own decisions) compared to the group of parents of children with TEA.

Durand et al. (2019) compared two groups of dyads composed of mothers and babies from 2 to 26 months of age: one made up of family members of an older child with ASD and the other made up of family members of an older child without ASD. Dyads of children with ASD relatives had relational difficulties more often, such as more significant constriction in their interactions, with their babies showing an increased chance of withdrawal behavior and mothers with higher depressive mood scores.

The data mentioned above draws attention to the relevance of care for families in which individuals are diagnosed with ASD, which may justify siblings being placed as a priority in health systems. However, there is still no consensus on how autism affects the families' lives in which there are subjects with this diagnosis. It is likely that this consensus will not exist, since each family is unique and deals in idiosyncratic ways with autism and all the effects it has.

In this sense, in the next topic of this article, autobiographical reports will be brought in order to focus the mentioned idiosyncrasies in the way of dealing with autism. The view will be different from that adopted so far, where an external epidemiological point of view, linked to terms such as 'risk', 'typical development', and 'atypical development' were predominant. Families will be seen 'from inside', based on their autobiographies. Thus, we can look at the situation from a new perspective: no longer related to the risk or negative impact of autism in the family. Contrarily to this, we will see how fathers, mothers and siblings of children with autism can help them get out of their isolation and enhance their self-therapeutic abilities (Maleval, 2017).

Autobiographies written by parents of ASD children

The analysis of autobiographical books written by parents of people diagnosed with ASD, whose children are George (Moore, 2006), Iris (Carter-Johnson, 2016), Jean (Ollier, 2015), Owen (Suskind, 2017), Sam (Moore, 2006), Théo (Gay-Corajoud & Ow, 2016) and Tony (Callaham, 1993) shows how all these people with ASD have been able to develop in different areas - intellectual, emotional and social - anchored in large part by the dedication of their families. In all of these books, the arduous struggle of these parents to detect and translate small behavioral pieces of evidence to understand their children is striking, betting that there was a sense in what seemed illogical. Their reports emphasizing the importance of their presence, both active and delicate, capable of transforming all small daily activities into therapeutic/educational opportunities, which required intense and constant investments from their participation, as they persistently need to try to summon their child with ASD to bond, awaken his interest in the world and help him to discover what could motivate him to open up to other people.

When commenting on the autobiographical material in the field of autism, Faria (2017) emphasizes the importance of paying attention not only to children with ASD but also to their families. For the author, children's autism impacts family life, and, in this sense, the need for support and care is not only for children but also for families.

The study of the families' autobiographies mentioned above leads us to realize how especially challenging the experience of fatherhood or motherhood can be when having a son or daughter with ASD. The particularities of autistic symptomatology often cause small daily activities to be referred to as epic, requiring parents to have a herculean and extraordinary effort, especially in children with ASD with more evident classical symptomatic manifestations. The day-to-day experience of these parents is often described in the autobiographies based on words like 'hell', 'calvary', 'suffering' and 'helplessness', which allows us to have an idea of the titanic dimension of these parents' suffering.

The lack of reciprocity in the interaction and the typical absence of answers about why the child does not speak or have apparently meaningless crises can often put these parents in despair, producing paralysis and the feeling of incompetence. This is what Jacqueline Berger (2014), mother of two children with ASD, tells us, stressing that parents, in a reactive tendency, may come to assume the posture of a 'Performing relative'. With this expression, the author sought to refer to a posture that frequently values efficiency and good performance.

Such a perspective invites us to have an empathize posture with these parents, making us realize that it is essential to build a support network around them and their suffering, whether through contact with other family members, friends or even health professionals. The writing and publication of autobiographies by parents can be interpreted as an attempt not only to share this suffering but also to have it recognized by others. We can say that it is this sharing and the recognition that allows them to move from suffering and helplessness to the possibility of investing in the relationship with the child.

In his autobiographical studies about children with ASD families, Bialer (2017) mentions a series of examples in which the attitudes of parents, mothers and siblings were fundamental for the insertion of children with ASD in the social bond. Thus, to the extent that, on the one hand, it is possible to look at the families of children with autism considering their suffering and, on the other hand, it is possible to seek to understand what is fruitful in their way of dealing with the child's autism, doors are opened to distance from a look like that of the 'refrigerator mother'. Below, excerpts from some of the thought-provoking autobiographies will be presented so that it can be seen that families have healing potential.

In the Suskind family (2017), the youngest son Owen is the one with ASD. Owen has a keen interest in Disney films, and the only word he speaks is *juicervose*. One day, the parents realize that such a word is the reproduction of a scene from the Little Mermaid film when the witch tells the mermaid that she must lose her voice to enter human life. Upon noticing and communicating this similarity to his son, Owen looks into the eyes for the first time in a year, subsequently presenting a gradual development of his speech. Then Owen started repeatedly watching the movie *Beauty and the Beast* and repeating *bootylyzwitten*, which could be understood when his mother deciphered that he was saying the title of the film *Beauty lies within*.

Concerning the example described above, we can emphasize the importance of parents betting on the beauty of an inner life, where there was apparently only a closed and almost impenetrable child. Far from being 'indifferent' and 'cold', as the 'refrigerator mother'

hypothesis suggested, Owen's parents demonstrated great sensitivity and exploited the therapeutic potential that Disney films demonstrated to have for their son.

To help to break Owen's autistic isolation, who was always watching movies and repeating the *scripts*, the family creates a 'family holding setting', that is, a space for welcoming and sharing the emotional meaning of the experience provided by the family. In this context, the videos are dramatized by Owen's parents and brother, each personifying a character, resulting in a place of pleasure and liveliness. The Suskind family portrays having underpinned an existence in which suffering could be transformed into aesthetic experience and in a shared human experience.

When presenting the autobiographical and literary writings of the non-speaking ASD child, Tito Mukhopadhyay, Bialer (2016) highlights the importance of Tito's mother bet on him believing that there was in him a thinking and sensitive subject. Then, she literates his son in Bengali and English, quite unlike the discouraging official prognosis she had received due to his severe autism. Reading this article, it leads us to realize that, had it not been for his mother's investment, Tito would not have been able to become a writer and, even, to be able to demonstrate in his productions such sensitivity and imaginative capacity.

Another family autobiography is that of Tony (Callaham, 1993), in which we are led to the discovery that his family started to use a tape recorder to communicate with him. It is interesting to see the singular aspect of each family in dealing with children with ASD and their way of being in the world. Tony's family had to be very sensitive to realize that the boy showed a different posture when listening to the voices of family members when they were recorded, as opposed to the usual lack of response to voices spoken without a tape recorder. Tony's parents revealed their investment towards him, there was a possibility of speech, communication and somewhere in the social bond beyond exclusion.

Tony has a younger sister, Renée, and her presence is essential in the possibility that his brother will leave his isolation. When she was only nine months old, Renée observed that her brother was staring at his foot. The girl then tried to imitate her brother's gesture and, subsequently, tried to interrupt his repetitive movements with his feet. Tony was not irritated or had a crisis: contrary to that, he burst out laughing. The two started a joint game, which could be repeated several times and contributed to Tony's development and his opening to the bond with other people. We see, in this example, the transformative potential of the relationship between siblings; while we have the news that one child can do a lot for the other. We can also see that the impact of having an older brother with ASD is not necessarily negative.

The case of the Charlotte Moore family (Moore, 2006) is particularly attractive to the theme of this article. Charlotte is the mother of two children with TEA, George and Sam. Both repeat scenes from films, with mimicked voices, sounds and standardized messages, without the possibility of spontaneous speech production. When asked why she had two children with ASD, Charlotte replies, "I don't know. And in a way, it doesn't matter" (Moore, 2006, p. 16). Charlotte's response invites us to take a complex and comprehensive look at autism, which can consider all the multiplicity of factors involved in the daily lives of those who deal with a child with ASD.

Still, within the scope of this topic, it is essential to point out that, even today, some people understand that psychoanalysis is an approach that blames the mother for the child's autism, probably due to those who were imprisoned in the 1940s and spread anachronically supposedly 'psychoanalytic ideas'. Andréa Werner, for example, Theo's mother and author of the blog 'Lagarta Vira Pupa' ('Caterpillar turns pupa' in English), raises this issue in the

articles *Autism, psychoanalysis and maternal blame* (Werner, 2012a) and *Autism: why to flee from Psychoanalysis* (Werner, 2012b). Given the publication of these articles, dozens of mothers expressed themselves in comments in which they were able to relieve the burden of an allegedly accusatory discourse. In the search for the cause of the child's autism, many mothers reported feeling guilty when they thought that the condition of being autistic could be due to maternal factors. Almost unanimously, these mothers highlighted suffering in the face of this discourse and reported that 'looking for the guilty' did not help them in any way to deal with their children's autism.

Among the comments on the blog, some stand out from mothers who reject psychoanalysis, often understood as a mothers-blaming approach. Some psychoanalysts also commented on the articles, in an attempt to undo this view, but what it seems is that many people do not have access to reformulations and advances within the psychoanalytic clinic, maintaining a closed attitude towards this perspective.

Final considerations

Given the above, we reiterate the need for professionals who dedicate themselves to the clinic and research on autism to have ethical and welcoming availability to the whole family. We also reiterate that one of the paths that psychoanalysis can take in order to deconstruct the image of the accusatory perspective of mothers and families is, on the one hand, walking together with researches that point to the suffering of these families and, on the other hand, knowing and focusing on initiatives by the very families that can encourage the growth and development of children with ASD. In the present work, we tried to promote this discussion based on two axes.

The first of these axes refers to the topic entitled 'The impact of autism towards the family'. It concerns the possibility of looking not only at how the subjectivity of the parents affects the child but also at the way how the child itself, with all his issues and singularities, affects the family. Thus, in the company of mostly quantitative studies, we realized the importance of paying attention not only to the parents of children with ASD but also to their siblings, considering their suffering in empathic availability.

The second of these axes refers to the topic entitled 'Autobiographies written by parents of ASD children'. It concerns the importance of turning to children with ASD and their families not only from outside, detached and specialist perspective, but also from inside. This perspective allows us to come to realize that, in families, we can often find a therapeutic and fruitful potential in the sense of an effort to remove the child with ASD from his isolation and to insert him into the social bond.

This discussion calls us to think about the importance of researches that focus on the study of families of children with ASD. The reflections developed here also lead us to some questions: do primary health care services have something to do for the families of children with ASD? How can we focus on these families, encouraging them to become partners and allies in the proposed interventions?

Furthermore, we must be open to realize that each family is singular and unique. Thus, although quantitative researches are fundamental in the sense of contributing to the formulation of public health policies, they cannot tell us much about what goes on in each family concerning their fantasies, fears, vicissitudes and victories. Statistical data, after all,

could not lead us to know the unique and thought-provoking paths that each autobiographies family found in their daily dealings with their children.

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