RECIMA21 - REVISTA CIENTÍFICA MULTIDISCIPLINAR
ISSN 2675-6218

MOURNING OF AN IDEALIZED CHILD: ATYPICAL MOTHERS OF CHILDREN WITH AUTISTIC SPECÉCTRINAL DISORDER (TEA)

LUTO DE UM FILHO IDEALIZADO: MÃES ATÍPICAS DE CRIANÇAS COM TRANSTORNO DO ESPÉCTRO AUTISTA (TEA)

EL DUELO DE UN NIÑO IDEALIZADO: MADRES ATÍPICAS DE NIÑOS CON TRASTORNO ESPECTRAL AUTISTA (TEA)

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e3112208
https://doi.org/10.47820/recima21.v3i11.2208

PUBLISHED: 11/2022

ABSTRACT

Currently, autism spectrum disorder has become better known due to the increase in positive diagnoses for it. With this, there is an increase in the number of atypical mothers who experience the mourning of the idealized "perfect" child. These mothers, after learning about their children's report, experience the stages of denial and isolation, anger, bargaining, depression and acceptance. in communication and social interaction, repetitive and stereotyped behaviors, with a restricted set of interests and activities. The cause of autism spectrum disorder still remains unknown. Scientifically there is no single cause, but the integration of genetic and environmental factors. Regardless of having a diagnosis, it is clear that atypical mothers are able to identify characteristics in their children, which make them look for professionals with the intention of differentiating what would be considered normal or stereotypy behavior. These mothers seek professional support for their children and consequently perceive the need for follow-up for themselves, due to the emotional burden they carry, the lack of a support network, the lack of empathy from society and the family, the unpreparedness of schools/qualified professionals. to deal with people with this disorder (ASD) among other demands.

KEYWORDS: Mourning. Atypical Mothers. Tea. Support Network.

RESUMO

Atualmente o transtorno do espectro autista vem se tornando mais conhecido devido ao aumento de diagnóstico positivos para tal. Com isto, observa-se um aumento na quantidade de mães atípicas que vivenciam o luto do filho “perfeito” idealizado. Estas mães, após tomarem conhecimento do laudo de seus filhos, experenciam os estágios de negação e isolamento, raiva, barganha, depressão e aceitação, O transtorno do espectro autista (TEA) é um distúrbio do neurodesenvolvimento definido por escalada atípica, exposições comportamentais, dificuldade na comunicação e interação social, comportamentos repetitivos e estereotipados, com conjunto restrito de interesses e atividades. A causa do transtorno do espectro autista ainda permanece desconhecida. Cientificamente não existe uma causa única, mas sim a integração de fatores genéticos e ambientais. Independente da posse de um diagnóstico, percebe-se que as mães atípicas conseguem identificar características em seus filhos, que a fazem procurar profissionais na intenção de diferenciar o que seria comportamento ditos normais ou estereotipias. Estas mães procuram apoio de profissionais para seus filhos e consequentemente percebem a necessidade de acompanhamento para si, devido a carga emocional que carregam, a falta de rede de apoio, a ausência de empatia da sociedade e da família, o despreparo das escolas / profissionais qualificados para lidar com os portadores deste transtorno (TEA) entre outras demandas.

PALAVRAS-CHAVE: Luto. Mães Atíticas. TEA. Rede de Apoio.

RESUMEN

Actualmente, el trastorno del espectro autista es más conocido debido al aumento de los diagnósticos positivos. Así, aumenta el número de madres atípicas que experimentan el duelo del hijo "perfecto" idealizado. Estas madres, tras conocer el informe de su hijo, experimentan las etapas de negación y

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aislamiento, rabia, negociación, depresión y aceptación, El trastorno del espectro autista (TEA) es un trastorno del neurodesarrollo que se define por una escalada atípica, muestras de comportamiento, dificultad en la comunicación e interacción social, comportamientos repetitivos y estereotipados, con un conjunto restringido de intereses y actividades. La causa del trastorno del espectro autista sigue siendo desconocida. Científicamente no existe una causa única, sino la integración de factores genéticos y ambientales. Independientemente de tener un diagnóstico, se puede notar que las madres atípicas pueden identificar características en sus hijos que las hacen buscar profesionales con la intención de diferenciar lo que se consideraría un comportamiento normal o estereotipado. Estas madres buscan el apoyo de los profesionales para sus hijos y, en consecuencia, se dan cuenta de la necesidad de seguimiento para ellas mismas, debido a la carga emocional que llevan, la falta de red de apoyo, la falta de empatía de la sociedad y la familia, la falta de preparación de las escuelas / profesionales cualificados para hacer frente a los portadores de este trastorno (TEA) entre otras demandas.

PALABRAS CLAVE: Duelo. Madres áticas. TEA. Red de apoyo.

1. INTRODUCTION

The objective of understanding the life history of these mothers, starting with the perception of the development of this atypical child, through the diagnosis of Autistic Espéctrum Disorder (ASD) and the post-report experiences.

According to the Manual Diagnóstico e Statistico de Trasntorno Metais (DSM-5), Autism Spectrum Disorder (ASD) is characterized by deficits in two central domains: social communication and social interaction and repetitive and restricted patterns of behavior, interests and activities. According to the Ministry of Health, the signs of the child's neurodevelopment can be perceived in the first months of life, with the diagnosis established around 2 to 3 years of age. The above statements state what was given after the questionnaire was applied.

According to Freud (1915), mourning has as characteristics the loss of a significant connection between the human being and his object, which is a natural and habitual mental event throughout the development of individuals. The proposal of mourning is not only restricted to death, but to the confrontation for Paulatin losses, whether true or metaphorical.

After the suspicion of a possible ASD, these mothers begin a process of mourning the "death" of their ideal children. When dealing with the grief generated in the family by a diagnosis, Franco (2015) reports that the grief that parents experience becomes a process of elaboration possibly slower due to the passion that parents have for the idealized child, who, upon discovering the disability of this child, feel as if they have lost the perfect child.

During the mourning process of these mothers, it is necessary that in addition to the support of family members, both they and their children, begin follow-ups with professionals convenient for this moment of great challenges. Such follow-ups will be essential for the child's better development and in the case of mothers, for coping with the whole process of mourning and the challenges they will have during their lives.

Moraes (2021) "points to the importance, in the autism clinic, of narcissistically welcoming and revitalizing the parents of children with ASD, usually so charged by feelings of anguish and helplessing and suffered due to the impact of the diagnosis and the daily challenges faced by them. The author highlights the relevance of a position of listening and ethics that aims to welcome the child and his family from his suffering. It is a perspective of "[...] social co-responsibility of the family in the construction of care, in the symbolic transmission and in the support of a critical position on the possible places and destinies of the child" (*apud* MERLETTI, 2018, p. 149)

2. METHODOLOGY

Taking into account the high rate of ASD diagnoses in *the network of* the authors of this article, the theme was considered a pertinent discussion in order to generate in readers an inclusive and empathic look for these atypical mothers who face such discrimination in various contexts.

The research methods used in this work were field research and bibliographic review, which, as described by The Brazilian (2003), is the type of research that makes use of scientific publications in journals, books, etc., in addition to the objective of summarizing qualitative research. In this article, quantitative research was also used, based on applied questionnaires. The results of this research are based on bibliographic research as well as on the results obtained through the applied instrument.

To collect material, questionnaires applied to 9 (nine) atypical mothers, volunteers, aged between 28 and 50 years, domiciled in the municipalities of Paulista and Recife, in the state of Pernambuco on September 15, 2022. In addition to the questionnaires, scientific articles and books were used.

3. THEORETICAL FOUNDATION

In a world full of children considered normal by society, we also find children who have Autism Spectrum Disorder (ASD), who are individuals who stand out for their differentiated attitudes. These behaviors can be interpreted by the social body as positive or negative, depending on the characteristics they may present.

According to Gardia, Tuchman and Rotta (2004), autism is not considered a disease alone, but a sensitive developmental disorder, by behavioral vision, with diverse etiologies and varying degrees of severity. Gupta and State (2006) point out that autism is among the psychiatric disorders with the greatest genetic clues.

Seize and Borsa (2017) state that the American Academy of Pediatrics advises that the investigation of signs of Autism Spectrum Disorder (ASD) needs to be conducted between 18-24 months of life, using standard instruments. It can be seen evidence of autism from the age of 18 months, they claim that Kupfer et al., (2009), investigating some premature measures that are identified in the child as: difficulty of focus, social interaction, mastery of gestures and position in communication and facial expressions, absence or reduction of typical games, habitual or continuous behaviors related to the body, hyposensitivity or hypersensitivity to noise, language, or movement with objects such as rotate and queue.

According to the Diagnostic and Statistical Manual of Metal Transfer (DSM-5):

> autism spectrum disorder is characterized by persistent deficits in social communication and social interaction in multiple contexts, including deficits in social reciprocity, nonverbal communication behaviors used for social interaction, and skills to develop, maintain and understand relationships.

Considering the characteristics that a child with ASD presents, it is understood that from the first observation of a stereotyped behavior, a mother who idealized the perfect child begins to experience feelings of which leaves her fragile and sometimes bewildered. Not knowing how to deal with the "death" of this idealized perfect son, this mother who identified in her child these behaviors, commonly begins her grieving process.

According to De Jesus Vidal and De Andrade (2021, p. 14) *apud* Kübler-Ross (2008):

> Kübler-Ross (2008), considering the process of mourning elaboration, says that it is necessary to experience five stages, namely: denial, anger, bargaining, depression and acceptance, which do not necessarily happen in this order, but it is common for the subject to go through at least two of them and, in some cases, it is possible to stay for a long time at the same stage or even a lifetime, as Taverna & Souza says.

According to De Jesus Vidal and De Andrade (2021) mourning is experienced in 5 stages:

> The first stage of mourning is denial, when the subject perceives the loss, but tends to deny the fact, seeking to find explanations so that he does not have to face reality. In the second stage, anger, the subject will realize that in fact this is happening to him but will face what happened with this feeling and with the question: "Why me?". The third stage is the bargain, the subject will look for something that posts or undoes evil, as if there was no other way out. At this stage, the subject is already calmer, begins a construction of the bond with the spiritual part and makes promises in an attempt to gain something in return. in the fourth stage, depression, the subject is exhausted, losing all hopes, beginning to feel the pain of loss when he finally faces reality. And finally, in the fifth stage, that of acceptance, the subject finally accepts the fact, stop fighting what happened and understands that the best is the overcoming of loss. Therefore, to stop denying reality, he accepts that he needs to face and move forward with his difficulties and possibilities.

Understanding that every emotional problem that an individual goes through, regardless of the reason/cause, there is no specific time for the resolution of such conflict, because each human being will react to his time, it is understood that an atypical mother also goes through the process of resolution, but this one, in most cases, does not have time to digest the news of a diagnosis and needs to react in helping her child's health.

Since the life of a child with ASD requires a lot of this atypical mother, especially her emotional mother, it is understood that she needs a good support network, and this network is made up not only of family, friends and belief, but also of professionals trained for this demand

According to Hoffmann, Müller & Rubin (2006), the social support network is vital for humans, understood as an interpersonal plot that models and is modeled by people.

It is necessary that this support network has the intervention of psychologists and/or psychiatrists. Based on the understanding that these mothers are experiencing mourning for the "death" of their idealized perfect children, this network can also count on the support of religion/spirituality that has been a great help, since it is directly related to trust in the end of the anguish caused by death, as Levin (2003) states.

Thus, it is understood that an atypical mother needs this support network so that she can endure and face all the emotional process that the development of this atypical child requires, knowing that the vast majority of this burden, this mother often carries alone because she could not support, that is, not having a support network to take to the competent professionals, education, home care, etc.

4. RESULTS AND DISCUSSION

The results presented below refer to a field survey, carried out through questionnaires containing 15 questions related to the theme in question. The population whose sample was performed is of atypical mothers, volunteers, who live in the cities of Paulista and Recife (Pernambuco).

Questionnaire:

1. How old is the child?
2. What did you notice about your child that made you seek professional help? And how long did the child's life realize?
3. How old was autism diagnosed?
4. How did you discover the diagnosis? How did that make you feel? What was your reaction?
5. How is the family's behavior towards the child?
6. What's your greatest difficulty in being an atypical mother?
7. Are you or have you been afraid?
8. Does your son study? Since you were old? Does the school give the necessary support?
9. How do you follow up on the child at school?
10. Was it easy to find a school that would take him?
11. Were there difficulties in finding a school that would give your child the necessary support?
12. Do you have a support network? What's your support network?
13. Does your child follow up? Where? Which professionals accompany your child?
14. Can you report a little bit of your experience, or report something that has marked you?
15. Do you have any professional follow-ups?

Questionnaire Responses

Below are the responses of the volunteer mothers, where they are identified with numbers from 1 to 9.

MOTHER QUESTIONNAIRE 1

1 - 6 years
2 - Called by the name she did not answer, did not release kiss, did not give goodbye, did not play functionally, 2 to 3 years
3 - 3 years
4 - I took to Neuro she gave the diagnosis of investigation and had the therapies did 3 months later we returned and she closed the diagnosis, I was quite sad, I cried a lot but I accepted

5 - The family came to understand more about autism and gave me a lot of support
6 - My greatest difficulty is lack of information, ignorance and lack of empathy of people with autistic
7 - I am very afraid of the future, of what it will be like when it grows, but I believe very much in the development of it
8 - Studied since 1 year 6 months stopped during the pandemic and returned this year the school of all support for the well-being and inclusion of it
9 - Her teacher is wonderful she is a neuropsychopedagogist, does elaborate activities for her
10 - Yes, the first school accepted but did not have the care she needed
11 - No, this was Laura's second school and it's been a totally different experience from the first
12 - Yes, My husband, my parents, my grandmother
13 - Yes, Cefope clinic, T.O, psychologist, speech therapist, physiotherapist, psychopedagogist, sensory, psychomotrician
14 - The moment that most marked me was the first sentence that Laura formed "I want to watch" I will never forget that day
15 - I've had it but not at the moment.

MOTHER QUESTIONNAIRE 2

1) 14 years and 10 months.
2) Developmental delay in general. The feeling that i didn't hear, or that, i selected the wanted to hear, say goodbye backwards. Playing dysfunctionally with toys, such as turning the wheel of the cart, not fixating on anything.
3) 2 years and 6 months
4) I already knew something was wrong. I felt sad, but not bereaved. I wasn't aware of what autism is in real, the cases of autism I'd seen were just those in the movies. I was called by the school and instructed to look for a neuro. Right off the corner, he didn't close the diagnosis, but he asked to start therapy with OD and phono.
5) At first, when I was a minor, I was more accepted. Today we are completely abandoned.
6) My greatest difficulty is impotence. I feel abandoned also by the typical mothers (in autism social life ends for our children, especially when large, consequently, for us as well). But in relation to atypical mothers I feel very welcomed and helped.
7) I have a lot of fears. We get older and they grow, getting strong, but without self-defense, without a notion of danger, without autonomy, all this generates uncertainties and more difficulty in dealing with them. But my biggest fear is to leave him. I'm so afraid he's going to suffer.
8) Not anymore today. I don't see any sense to him anymore. I see more suffering than it helps in cognitive development or interaction. He started when he was two. When he was in school, he had someone to accompany him. Now support needed, no. Schools are not yet prepared to deal with differences, let alone moderate to severe autism. There's still a long way to go for inclusion in schools. It would take a change at ministerial level in the curriculum of pedagogy and undergraduate courses, with the inclusion of essential subjects, for the teacher to leave college, with minimal notion of how to deal with these children. There is still a long way to go for inclusion in schools and other social environments.
9) He's not studying anymore. But he would probably be with a therapeutic attendant from the clinic where he does the therapies.
10) On the private network, yes. Not in the public network. I was very welcome.
11) The necessary support I found on the public network. I was fortunate enough to find a school that had a psychologist committed to the cause and a good appeal room at the institution. That made it a lot easier.
12) Yes, but precarious. In my family, I count on my daughter and my son-in-law, in addition to his father financially (these children are very expensive). I count a lot on the support of my

friends, atypical mothers, who always help me, both psychologically and in practice, with advice, directions, new information ... it's like a sorority. One holding and lifting the other when necessary.

13) Yes. At the Somar Clinic. Occupational therapy with sensory integration, speech therapy, pedagogy, psychopedagogy, motor activity, aquatic therapy, daily life activities (ADLs)... all these therapies are related to ABA, TEACCH, PECS, PROMPT, among others.
14) That's the hardest question to answer. What I feel is that he trusts and relies a lot on me, everything that happens to him, the first person he runs is for me. Sometimes I feel like it's an extension of him. I live for him and for him. I have 2 more children and 1 grandson, I love everyone unconditionally, but my Paulinho, you need me more.
15) Yes. But i'd need a lot more.

MOTHER QUESTIONNAIRE 3

1) 7 years old
2) already knew about autism, by having a nephew, I began to notice that she had characteristics, did not used to follow with the look, did not mind having contact with people, did not answer by name, with 5 months I began to notice the first signs.
3) When I was 2 years old, I closed the diagnosis.
4) I was not surprised, because I already had an affair in the family and understood how it was, I was not happy, but we focused on the treatment.
5) They seek help despite sometimes discrediting their ability and lacking patience.
6) Adaptation of my routine to the treatment of the child, in view of the lack of support.
7) I'm afraid of the future of not becoming an independent adult.
8) She has been studying since she was two and a half years old, and the school tries to help, but she has tA that is provided by the health plan after putting it in court, which greatly facilitated the school relationship.
9) She does ABA, has At and ABA supervisor who visits the school and makes adjustments in the child's follow-up.
10) The first school did not support, in her therapy I met a mother who had a kindergarten school and changed her school, then improved because they experience autism at home seek to help more.
11) A little, but in therapy I found the mother who had school and helps me a lot by understanding more.
12) My mother who helps, in the moments she is not in school or therapy
13) She underdoes follow-up at Somar, has all treatment prescribed by the neurologist, ABA therapy, occupational therapist, piscomotricity, piscicologico, ADL, speech therapist, motor and aquatic stimulation.
14) It marked me the day a mother yelled at my daughter on the playground and reported that she was getting in the way of other children's play.
15) I need it, but at the moment I can't prioritize that.

MOTHER QUESTIONNAIRE 4

1) 4 YEARS OLD
2) He didn't respond to simple commands, he didn't interact, he walked on his toes
3) 2 1/2 years
4) I figured, I just wasn't sure, and I wasn't even diagnosed. It was a mixture of feelings, but I remained strong to seek professional help that he needed
5) Not everyone in the family can handle behavior and especially crises, every day there is something new to learn.

6) Not being able to reconcile time, keep working out for some time, nights of sleep and exhausting tiredness.
7) Of not being able to handle it. Of not being able to take care 100%. My son didn't develop.
8) Yes. Since I was three. No. It's more of a difficulty, I feel that the school is not prepared, able to develop it. I say this based on the various situations that have happened.
9) It is made by a teacher and an TA that accompanies you in the classroom.
10) Not so much, in fact, today, the difficulty is being in keeping him in the little school.
11) As time goes by, I say yes. Even the school is called inclusive, there is a lack of qualified professionals, adequate environments and etc.
12) Yes and no. I just have the father who is the only support network that can still handle everything
13) Yes. In a clinic specializing in ASD. He is accompanied by a psychologist, psychopedagogist, speech therapist and occupational therapist.
14) It's hard, it requires patience, it requires calm, it demands you. It's a daily construction! What marks me and I think will always mark me are the almost constant crises. That's it.
15) No.

MOTHER QUESTIONNAIRE 5

1) 10 years and 4 months
2) As a first-time mother, in the first years of life, I saw my son develop normal, until at 1 year and 5 months, he had a regression in development (he stopped talking, he no longer made eye contact).
3) After investigations the diagnosis, came at the age of 5.
4) At first, with the fact that he stopped talking, it was what bothered me the most, I looked for a speech therapist and pediatrician, but the supposed diagnosis of autism came through a psychologist; (I was supported and enlightened). My first reaction as a mother, was to chase knowledge and treatments, I didn't have time to comment, I wanted to change everything, to reverse the situation.
5) Today, thank God it's good and no, it's just autistic, we live empathy.
6) My greatest difficulty is getting treatment, because it is not cheap, also the lack of empathy and capacitive in society saddens me.
7) I'm afraid of death, I think a lot about the future, my son's adultness (prejudice).
8) Yes. He started school at the age of two. Nowadays he is in a good school, a teacher helps me a lot, my son is literate, accompanies the class and he is currently in 5th grade.
9) He sits next to the teacher, the questions in the test are more concrete. He has a pedagogical reinforcement, is hyper welcomed by all. It's six years in the same school, the family schoolwork is good. We are always in touch with david's development and learning.
10) At first, Yes, I had a lot of trouble with the first school, until I got the current school, which received it with great affection.
11) There is no perfect school, the support is never 100%, but within the reality of the majority, I am a little satisfied.
12) My biggest support network today, are atypical mothers (groups that fight for the same cause).
13) He has always done follow-up in NGOs (guardian angel) and in clinics with more popular price and my commitment at home that is fundamental.
14) Yes. In 2021 my son was awarded the 2nd best in the class with excellent grades.
15) Today I (mother) do psychological follow-up because of anxiety. Atypical mother's life is not easy.

MOTHER QUESTIONNAIRE 6

1) 11 years and 9 months
2) My daughter began to have a repetitive behavior and the handling of something in her hands. Ever since I was three years old, he's always covered his ears or grabbed me when he was too loud. Now between the age of 5 and 6 years was that it came to be stronger (I noticed) these reactions.
3) 7 years old
4) It was hard. I didn't want to accept what the reality was. When i was looking for a neuropediatrician, I made observations, questions and diagnosed it there. It was a feeling of sadness, because until she was 4 years old, she was a smart, observant, outgoing child, played with her siblings, related in the church, in the children's department. Soon I didn't realize, first at jesus boy school, where I was called to talk to psychologists about school achievement, who would soon seek psychological help. I asked for guidance, because even being a mother, it was a new case of how to help her develop in areas she can develop.
5) The family reacted well. Adults treat her well and usually only the children in the family walk away, and it hurts a lot in my heart. My daughter doesn't interact with children the same age. The absence of the father, male figure is harmful.
6) My difficulty is in everyday life, in the activities that are expected of an 11-year-old child. There is a need for special attention and treatment. Society is currently accepting more, and the rights acquired by autistic people have helped parents in their upbringing and education.
7) I still have her future.
8) Yes, he does. Since I was 2 years old. No. The school still does not give the expected support, desired. Some teachers have learned, out of personal interest, to work with them.
9) Good. As she, my daughter, has been studying for years at the same school, teachers are already aware of the limitations. Teachers need specialized support, when it is offered, surely, autistic children will have greater development. Inclusion was a very good determination. All you need is specialists in this area, to better use, performance, etc.
10) Yes. Most schools are accepting social inclusion, especially in private schools.
11) Yes, because most schools have not yet qualified to work with autistic people. I know of difficulties, because every autistic person is unique.
12) Yes, UNIMED Recife
13) Yes, CEFOPE (Magdalene). Professionals: psychopedagogist, speech therapist, psychologist, psychomotrician, ABA approach. (The lack of professionals in the clinic has led to the performance of two areas).
14) Thank God, I have a peaceful, peaceful, harmonious coexistence with my daughter. She obeys, feeds well (likes), sleeps well. He just doesn't like to leave the house. He's very fond of music. She learns easily, she learns easily, she's rhythmic, she's got a good voice. I would love to work music. She has a good hearing and that makes me police myself. Travel, walk, have lunch in a restaurant. Our relationship is healthy. I decorate Bible verses with her and always try to talk.
15) No. Now when I'm at CEFOPE, psychologists always talk to us, so I ask for guidance.

MOTHER QUESTIONNAIRE 7

1) 7 years old
2) At first, he had speech delay. The milestones of his baby phase were sharp, he looked into the eyes, he was watering, he was smart in visual perception. He didn't crawl, he's been holding on to his house stuff, and he's been walking. But when it came to speaking, there was a delay. At the age of two and a half, all he talked about was Mom, Dad, water and Grandma.

It was a very simple vocabulary for a child his age. He's supposed to be trying to form sentences. Then during this period I looked for a speech therapist even without diagnosis, his first contact with a professional was like this, to help us in this speech delay. Besides the speech delay, there were some behaviors that we did not realize but that she was punctuating throughout the meetings, like attachment to some objects, excessive crying in therapies and lack of concentration.

3) After a few months of follow-up with the phonoadiologist, I took him to the neuropediatrician at 3 years and 3 months that was when I received his diagnosis officially.
4) It was a fight against time. For me it's like I had lived the mourning before the report, when I had the diagnotic in my hands, the first day I was sad. It's no use saying I didn't live the grief, because every mother lives the mourning, she just can't let this mourning extend for long, because then you're wasting quality time and then you should roll up your sleeves. After a week I reacted and rolled up my sleeves.
5) I told relatives and friends in a quieter, simpler and succinct way, not out of shame, but so they wouldn't think he was poor and doing everything he wants. Now they follow the letter what was proposed, comply with the rules, not go through the orders.
6) First is to live the inclusion. Contrary looks, they think you're a spoiled child.
7) I wonder if I'm educating correctly.
8) Lucas has been studying since he was two. The school gives me a lot of support.
9) It has the necessary support. You can read and write.
10) He goes to school that I work for, and I fight for inclusion.
11) Not because he goes to school where I work.
12) I have a support network, yes. I have someone who works at my house, my mother-in-law, my mother and my grandmother.
13) Yes. In a clinic in Paratibe (Paulista) with speech therapist, T.O, psychologist, psychopedagogist and physical educator.
14) What marked my life a lot was his graduation from ABC, for me it was very exciting because he couldn't stand to pick up the pencil, it was a big challenge for me. To see him graduating, reading and writing perfectly, was extraordinary.
15) I go to therapy every 15 days with a psychologist. I wanted everyone to have the opportunity to do psychological follow-up because it would help a lot. Therapy is part of my day-to-day life.

MOTHER QUESTIONNAIRE 8

1) 7 years old
2) Lack of social interaction and speech delay
3) 2 years and 9 months
4) The discovery was confirmation (deep down I already knew). At first, I was in "mourning" then I went to fight.
5) Normal
6) Dealing with prejudice
7) Yes
8) Studies. Since I was two. The school supports it.
9) He has a therapeutic companion that the clinic where he does therapy directs to school and the school has a resource room.
10) Yes
11) No
12) No
13) Yes. Space therapy, from Monday to Friday he does sessions of Occupational Therapy (three times a week), sensory integration (twice a week), Speech Therapy (Three times a week),

Psychomotricity (twice a week), Psychology (twice a week), Psychopedagogy (twice a week) and ABA therapy (twice a week)

14) We follow a daily routine of therapy in the morning, the afternoon school and the night he walks needs to take a sleeping medication because he developed ADHD and the impertinability is still very evident, even though he is taking medication for concentration and attention. When the effect of the medication ends, it's like he can't control his body. He can't stop when he's on medication, he can't concentrate on anything.
15) No

MOTHER QUESTIONNAIRE 9

1) 7 years old
2) In the first year of school at the age of 2 and a half, the school reported some behaviors of irritation, low frustration, impulsivity and hyperactivity.
3) The first report was at the age of 5
4) The biggest scare was when the school complaints started and when talking to a psychologist friend, she made it clear that he was autistic. It was a shock to me and the whole family. I, though I didn't believe, I sought medical advice, since my husband, my mother and mother-in-law who cared for him thought he didn't need any follow-up. And this denial got in my way a lot because instead of having support I found a lot of resistance and denial.
5) Today the family accepts more and has understood some particularities of ASD. But it's pretty hard when he's in crisis. Not only does it disorganize all over that are around.
6) My biggest difficulty is having to work and depend on other people staying with him. I have a lot to learn, but I'm the only one to be interested in the subject, but what's the point of so much knowledge if those who stay don't seek the same and don't care what I say. But I can't charge because you have no obligation to stay with him and they still help me as they can.
7) I have a lot of fears. Fear of prejudices, fear of comorbidities, fear of the future. Afraid of dying and leaving him. Afraid of not understanding perfectly and making the picture worse rather than helping. Afraid he can't give him the treatment he needs.
8) Yes. Since I was two and a half. The school was very welcoming as soon as we arrived without prejudice, but we feel that the team is still unprepared and does not know how to deal with some behavior of my son. I'm always looking for meetings to find ways to help him and listen to the teacher's complaints. But some suggestions I found were not accepted by the school making our relationship difficult.
9) The school has a psychologist who says she's with my son. The psychopedagogist is responsible for the PDI's and treats children with difficulties in the counter shift, but so far she says that I son did not present difficulty. Faced with the complaints of the behavior school, as it attends privately and has ABA supervision, I contracted her for a while to help the teacher deal with him in the classroom, but throughout the service provided never went to the school to see him in the classroom and understand certain behaviors. For this reason, I canceled the service and October 4th since year he starts with a new professional. I had asked the teacher not to force the cursive lyrics and make adaptations for him, but I was unsuccessful. Just as I suggested paying an At to go twice a week and the school didn't accept it because it wasn't a school employee. When she suggests that the school then put it on them, she says that my son is independent and doesn't need support.
10) No. I've looked through a lot of them. We've been through a lot in schools. Your behavior was once a reason to leave school. In the visits to the schools, I received a lot we are not prepared, the school already has autistic in the room and we are without vacancy. We are obliged to receive. And after much searching I found a school that at first was very welcoming.
11) Yes. The current school even as already reported above to the school does not make necessary adaptations that parents or children may question. But my son has report and

adaptations is his right and the other children as well as his parents need to understand, because it is part of the inclusion process.

12) The support network I have are some mothers I had the opportunity to meet and today we help each other.
13) Yes. Today he is accompanied by a physiotherapist, psychomotricity, phonodiologist, psychopedagogist, psychologist and music therapist.
14) My son's last report was given the diagnosis of LEVEL 1 ASD, TDHA and TOD. The TOD is still under investigation. Despite being level 1 and having a good understanding is a difficult child, strong personality, low frustration, impulsive and irritated at times and this is very difficult to deal with at times. We have sought to follow the psychologist's guidance with certain more emergency demands. For example, school complaints have reduced when we have positively reinforced some behaviors on the day. Before going to school, we promised some positive reinforcement of his interest and we promise to win and he has good behavior and his behavior has improved. We start daily and then increase the time or leave more powerful boosters for the weekend. Ex. Monday and Tuesday = something that is not Super Attractive. Fourth, fifth and sixth = something more reinforcing. Then only on Thursday and Friday, then only on Friday. That is, we will gradually increase and when we feel that we are prepared we reduce the boosters because the intention is that then we no longer need it. What marks me most is when it disorganizes seriously for something that happened or did not happen and that takes too long. He cries for a long time, says he wants to die that he just wanted to have peace. I confess that it is very difficult to see him like this and often I do not see myself prepared to help him, but like every mother making mistakes or hitting do not give up.
15) I was being accompanied by a psychologist, but unfortunately because of her work and her availability I had to interrupt.

After the questionnaires were applied, it was identified that atypical mothers have children between the ages of 04 to 14 years and most perceived the common stereotypes of autistic species disorder (ASD) of their children within the time expected for discovery. All are regularly enrolled in school under the inclusive perspective, all of which undergo multidisciplinary follow-ups, among them are: speech therapists, psychologists, psychopedagogists, neuropediatricians, occupational therapists, physical educators, among others.

It is noticeable in all mothers have common fears among them that permeate between future, death and the prejudice that this family nucleus will face throughout life. These mothers do not undergo follow-up with professionals who are able to do so but are aware of the importance and need to do so. In the answers given also indicated to have a support network varying between family, friends, and hospital network.

5. FINAL CONSIDERATIONS

Through this study, considering bibliographic research and field research, it is identified how these atypical mothers develop fear of the future of their children when they consider prejudice and lack of empathy that since the first stereotyped behaviors are already present in the social group in which this autistic and this mother are inserted.

Having a child with Autism Spectrum Disorder (ASD) creates an emotional burden on the mother who even checks out her ability to care for her children. Many carries with them issues related to the "death" of the idealized perfect child, that is, they experience mourning, but they do not see themselves bereaved.

It turns out that having a support network is of paramount importance in the grieving process of these atypical mothers, who by having this help can withstand the difficulties they face throughout their lives.

It is concluded that with the discovery of a child with Autism Spectrum Disorder (ASD), atypical mothers experience fear, frustration, shame, sadness, revolt, denial, among other emotions that make them develop a psychological framework where it is necessary to follow up professionals who help them to elaborate, name and adapt to this new reality and support network so that they can deal with everything that causes autistic spectral disorder (TEA).

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