

Experiences of families of children with autism spectrum disorder

Abstract

Autism is a complex disorder characterized by a series of conditions and symptoms that classify it as an autism spectrum disorder, with relevant physiological and biochemical factors, and core symptoms that include social deficits and restrictive/repetitive behaviors. This condition triggers changes in family life due to the child's needs for growth and development. We sought to report experiences of families of children with autism spectrum disorder and their life changes. Descriptive exploratory study with a qualitative approach, which was carried out at the Associação de Equoterapia de Alagoas, located in the city of Maceió-AL, from June to July 2022. Interviews, genograms, ecomaps and life narratives were used for collection. Five families monitored by the institution and whose children were diagnosed with ASD and aged between 5 and 12 years participated. The results reveal the understanding of the daily lives of parents of children with ASD with the aim of promoting and listing contributions to nursing, with a view to enhancing more representativeness and autonomy in the care of children with such specificities, with the intention that in the consultations themselves of nursing that screening is increasingly effective. The study also raised reflections and challenges in facing changes in the face of children's needs in the face of challenging social and health contexts.

Keywords: autistic spectrum disorder, child, family, daily life

Volume 9 Issue 2 - 2024

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Received: May 25, 2024 | **Published:** June 13, 2024

Abbreviations: ASD, autism spectrum disorder; ADDM, autism and developmental disabilities monitoring

Introduction

Autism is a complex disorder characterized by a series of conditions and symptoms that frame it as Autism Spectrum Disorder (ASD), including relevant physiological and biochemical factors, whose core symptoms include social deficits and restrictive/repetitive behaviors.¹ The etiology is still unknown, however, the current trend is to consider it as a syndrome of multicausal origin involving genetic, neurological and social factors of the child.² Due to its high prevalence, ASD has been the subject of global debate. According to the Autism and Developmental Disabilities Monitoring (ADDM) report of 2020, the prevalence of autism has increased to one in fifty-four eight-year-olds.³ This condition was considered relatively rare for years, with a prevalence of less than 1 in 1000 children, however, today, it has an estimated rate of 1 in 160 children and seems likely to increase in the coming years.⁴ The essential characteristics of ASD consist of atypical impaired development. It involves alterations in the sociocommunicative area and the presence of a restricted and stereotyped repertoire of behaviors, activities and interests.^{5,6} ASD leads to impairments in the areas that comprise social interaction, language and/or communication.

This condition triggers changes in family life due to the child's developmental needs. The diagnosis of a disorder, especially in the case of children, is an impactful situation that can have repercussions in terms of changing the daily routine, readjusting roles and causing various effects in the occupational and financial spheres and in family relationships.^{3,6} The family then turns to the care needs of the child with ASD, and generally, the main caregivers, the mother and father, stop taking care of themselves, adjusting to the child's condition of vulnerability and dependence.⁷ The aim is to understand the needs of

the family (fathers and mothers) when it comes to caring for children with ASD, given the changes they have experienced, in order to identify new forms and lines of care for both the child and the family, all in order to contribute to nursing care and increase the role of the family, giving more visibility to the care and assistance provided. That said, this research aimed to report on the experiences of families of children with Autism Spectrum Disorder and their life changes.

Methodology

A descriptive study with a qualitative approach, carried out at the Alagoas Equine Therapy Association, located in the city of Maceió, Alagoas. This institution was founded on May 10, 1989, and is a non-profit civil entity of a philanthropic, assistance and therapeutic nature, based in Brasília, the capital of Brazil, which operates throughout the country. This research is part of the master's thesis presented to the Postgraduate Nursing Program of the Nursing School of the Federal University of Alagoas. This institution assists 26 families of children with ASD. To be included in the study, fathers and mothers of children diagnosed with ASD, aged between 5 and 12, who are accompanied by the Alagoas Equine Therapy Association, were invited to take part, taking into account the length of time since diagnosis, family transitions and the child's atypical growth and development phases, and who are regularly monitored by the institution, making up 5 families.

After approval by the committee (No. 5.91.849 CAAE 56353521.1.0000.5013), the participants were presented with the informed consent form, in compliance with the rules governing research with human beings, respecting the ethical principles of autonomy, beneficence, non-maleficence and justice. Participants were guaranteed total anonymity and were free to withdraw their consent at any time, thus ceasing to take part in this study.

Data collection took place from June to July 2022 and followed the following steps.

- I. Immersion in the setting:** A time to get to know the environment and the routine established between therapy staff and patients. It took three days to observe the dynamics and the possibility of being perceived as a researcher by the children's parents. This construction was important and necessary for the stage of collecting life story narratives;
- II. Knowledge of the target audience through medical records:** Consultation of the children's medical records, in order to get a sociodemographic profile of each child and to be able to list which ones would meet the requirements for the research;
- III. Identification of the families according to the inclusion and exclusion criteria:** Next, with the demographic data already captured, a refinement was carried out, choosing by age of the child and diagnosis defined for ASD; excluding those who were not within the age range, did not have a closed diagnosis and did not agree to take part in the study.
- IV. Obtaining the ICF:** During this same period, the Free and Informed Consent Form was organized with the study information for the appreciation of the family who agreed to participate; after consenting to participate, the participants who agreed to take part in the study signed the ICF. Participants could choose to withdraw from the study at any stage, without being penalized, in accordance with Resolution 466/12 and Resolution 510/16 of the National Health Council.
- V. Invitation and scheduling of interviews:** The families previously selected were invited to take part in the study. The confidentiality of the study has been preserved and there will be no public disclosure of results that would allow the research participants to be identified.
- VI. Preparing the location and materials needed for the interview:** The location chosen was a space within the association itself, since it has a well-wooded and peaceful environment, which is more conducive to families accepting to take part. Among the materials used were a voice recorder and chairs from the place itself so that the narrative could flow;
- VII. Conducting the interview:** Immediately after the project was presented together with the ICF, the recording began with the first trigger question, starting the narrative and allowing the participant to feel free to speak as much as they wished;
- VIII. Interview transcriptions:** The Reshape Platform, <https://www.reshape.com.br/>, was used to carry out the transcriptions, after which corrections were made, the transcriptions were re-read and they were brought into line with the cultured norm of the Portuguese language.

They were scheduled and guided by the life narrative method, which was based on the study by Bittencourt et al.,⁸ that brings as the main method for the construction of his study in question; in this way, audio recording material was used, with authorization through the ICF and communicated to the parents, to capture the parents' testimonies about the whole context with ASD. During the interview, two trigger questions were asked, one at the beginning of the interview and the other at the second moment when it was realized that the interviewee had already answered the first question: 1) Tell me about your child's life from conception to the present day? 2) What are the main needs you identify in your child? These questions were asked so that the

families could access and create a timeline with a starting point up to the present day. These questions act as triggers for the memories of our narrator interpreters. The pre-script involves three moments: their personal trajectories, where they tell their entire life trajectory in a chronological line; the trajectory of the diagnosis, all the paths taken, the situations they faced to discover the diagnosis; and after the diagnosis what changed, from that moment on a new situation begins, how they dealt with all the changes in their daily lives.⁹

Results

The stories told by the family members of people with ASD were organized according to their realities and experiences. The first family described how their life was all about their child.

1st family of children with ASD: "My life is all about my son"

Mother, 38 years old, married, completed high school, previously worked as an administrative assistant in a company. She lives in Maceió with her 37-year-old husband (an administrative assistant) and their 6-year-old son. Her son with ASD became pregnant at the age of 31 and she reported the following events during this pregnancy:

It was a very smooth pregnancy. At three months I had a urinary infection, which was the only thing I had, but the pregnancy was super smooth. He was born at forty-two weeks. I think I felt contractions for about a fortnight, but they were very mild, I didn't really feel any pain, but the bag burst and I stayed in the maternity ward. But I lost a lot of fluid, because the bag burst, I think around five in the afternoon, and he wasn't born until half past six in the morning.

As for the birth, she explained that until around the first year of his life he showed no changes in his development, but that she later noticed some signs of the interruption of words previously used by her son as a form of communication.

He was born quietly, he cried, everything was fine. Up to a year and a half or so, he developed as normally as any other child. At about nine months he was already speaking a few small words and at a year and a half he stopped speaking words. When he watched the DVDs, he would sing a few bits of the songs, but the words he already knew to speak to us, it was as if he had forgotten, he didn't speak them anymore.

Other warning signs were their behavior when using toys:

Then I started to notice that he played a lot with the cars without any function, he would put the cars upside down, lie on the floor and take the wheels off. The little balls we bought, those colored balls, when we went to play, he would scatter everything on the floor, he wouldn't pick up the mixed colors, to this day if he picks up a yellow ball, all the ones he picks up have to be yellow.

Still on the subject of signs, the mother also talked about aspects relating to her son's interaction, which led her to search for information on the internet about what might be happening to him:

He no longer looked at us when we called him, he didn't seem to listen when we spoke to him and then I started following a mother on Facebook who said her son was autistic. She gave lots of tips on her page. I started researching and saw that he had some characteristics. I went to the doctor, but the doctor said that each child had their own time, that up to two and a half years old this was normal, because if he sang, he didn't have a speech problem. But then it went on and on and when he turned two and a half I decided not to wait any longer.

With regard to the signs, she went in search of a diagnosis to find out what her son really had. She says that one of the first professionals she went to was a speech therapist who assessed him, but referred him to a neurologist to find out whether or not he was autistic and it took about a year and six months for an answer, all because of her health insurance.

We took him and when we got to the room with the speech therapist, all I said was that he doesn't behave properly and then she started her assessment and from her assessment, she had the same suspicion as me. Because the health insurance thing is very complicated, they've never diagnosed him, mainly because most of the neurologists on the health insurance are general neurologists and not neuropsychiatrists, so they say they're afraid of giving a wrong diagnosis.

For the mother, the moment of diagnosis was very long and at the same time frustrating, due to the delay in the professionals coming back and because it was never conclusive, something that made her aware of what her son had: It's just that I'd rather have an early misdiagnosis because the treatment won't be bad for him than a late diagnosis, because then it'll really hurt. So I went to three doctors who said he was autistic, but they didn't give it to me in writing and I didn't like the way he said it, because he said it as if I were someone else and not the mother. Because if I'm the mother and I'm looking for a diagnosis, he came to me and said:

"Tell the speech therapist that your son is autistic". That's what he said, and straight away he started giving me medication. So I didn't go back and looked for someone else again.

As she recounted her story, she revealed how difficult it was to know and recognize her son's signs.

I'm not going to lie, I cried a lot, but I was really afraid that I wouldn't be able to cope, because he didn't say anything... I had to time when he would eat and if he felt hungry, he wouldn't say, he wouldn't point, he wouldn't ask, I had to find out what he was feeling, so it was a very stressful time. Today he can tell me if his stomach, ears and head are hurting. So it's all a bit easier, but the diagnosis was easy for me. I think it was more complicated for the father than for me, in my opinion he still doesn't want to tell me. I'm not sure he accepts it.

In the case of family two, it emerged that the spouses have a conflictual relationship due to the change in their lives as a result of their daughter's diagnosis of ASD. The father doesn't accept the fact that his daughter has this specific condition. The daughter is closer to her mother and their relationship is very strong, showing that the mother-child relationship is constant and fluid, as described in the story below.

2nd family of children with ASD: "My daughter was very quiet when she was in the ICU"

A 35-year-old mother, female, married, complete higher education, trained as a pedagogue. Previously worked in a school for special needs children. Resides in the city of Maceió. Her 40-year-old husband works in sales. She became pregnant at the age of 32 and reported the following events during her pregnancy:

She was born at Santa Mônica, a premature baby, and the bag ruptured and I felt pain, so I went to Nossa Senhora da Guia at 6 a.m. When I got there, the doctor said I was going into labor, but I hadn't dilated, so I went to ask Mônica for a rush delivery, right? And when I arrived at Santa Mônica, I arrived at Santa Mônica at 7.45 a.m. and even with the document, Nossa Senhora da Guia gave me a caesarean section.

The mother mentioned how tense and complicated the hours before her daughter's birth were. From the countless hours of waiting on a stretcher in the corridor, feeling a lot of pain, between one doctor and another, time passed and she became more and more nervous:

During labor they put me on a stretcher and left me there, the doctor said she was going to change the shift and I had to wait for another doctor to arrive, the other doctor arrived at ten o'clock in the morning for a change and my mother was very nervous when I was alone, and my mother said, but my daughter needs help, she's bleeding a lot, she's in a lot of pain. But my mother spoke to the doctor, and she said, but there's nothing I can do, and she left, and another doctor arrived saying that she had lots of normal deliveries to do and I wasn't going to look, so my delivery took place at half past five in the afternoon.

During the complicated delivery, her daughter was born with some problems as a result of the long hours of waiting and she recounted the story of one of the doctors who attended to her while she was still in the hospital corridor:

We're going to give birth, but the pressure is too high and she took my daughter out prematurely and when she took my daughter out she was purple and lifeless. She's awake, because she swallowed a lot of amniotic fluid with the bag that ruptured and it took her a long time to get it out and my daughter was purple medically, you have to cheer her up and she didn't cry, she was just purple Combo.

As the days went by, the mother noticed some signs, even though her daughter was still in the ICU, she had already noticed something different because she had worked in a school for students with disabilities, which also received children with ASD:

As I'd already studied and worked with special children, I said to myself, there's something wrong with this girl, but I wasn't sure what syndrome my daughter had, so I went to look for information on the internet. That's when I found out, when she was a year old, she had a severe seizure and I went to the neurologist.

Seeing the signs, she went so far as to say that during the period she saw that her daughter had many limitations, such as the fact that she didn't pee or defecate and, most worryingly, she didn't have the primary sucking stimulus for breastfeeding, even if it was by milking:

She didn't pee or defecate. She was being induced by a feeding tube. So that she could feed herself, because she didn't have the strength to suck, we kept putting her on the dropper. Then she was very thin and very weak.

Between visits to various doctors, she says that the doctor was the one who actually diagnosed her with autism: She's been to many pediatricians and I haven't found out. Then my friend said, "I'll help you, give me your daughter's full name and I'll make an appointment with the neuropsychiatrist. She tried to get me an appointment at CORA. I managed to get an appointment at CORA and have treatment with her. She ran several tests and told me that my daughter was autistic.

He also said that due to the many situations he had already faced and was facing, he was asking for a solution from the government itself and from public policies on improving accessibility for autistic children in schools and in care:

Today's challenge, which I'll leave you with in this recording. It's for the government to wake up to specialized schools for autistic people. Teachers don't know how to deal with them because autistic people are deconstructed by noise, depending on the degree. They talk a lot in class, they don't sit still for long.

Still on the subject of public policies regarding access to education and health services, she spoke of the challenges of finding professionals to help her daughter, for example, dentists, nurses and others, and at the same time, of finding schools and/or teachers in secular schools who were prepared to help children with ASD.

The big challenge today is to find a school for autistic people, to find a nurse, to find a dentist, for example, my daughter is ten years old, I take her teeth out at home, so far I've been to the dentist. Eita, but I can't see her because she won't let me, only if she would let me, it's more like a tooth, but the tooth lets me talk, what? Ah, but to fill her tooth, it has to be with contrast. Then you have to look for another professional, you have to have a doctor, you have to give her something to sleep on, so that I can fill her tooth, yes, but how do I do it, then we don't have one, we have to look for a clinic, then one person plays off the other and we sort it out, for example, a dentist for autistic patients.

Still on the subject of accessibility, the mother said that she felt uncomfortable with the baby changing facilities in shopping centers, such as the mall, because they were not available for older children with specific needs, as her daughter has, and so she told of some difficult moments in this regard.

I think that wherever there is a changing room, it should be adapted for both drinking and special children so that we don't get ignored in the changing room. There should be a large section because it's not just wheelchair users who wear diapers. I'm the mother of an autistic child and I have to say it's not easy. The third family made it clear that the family's daily life changed in the face of ASD, during the course of the diagnosis, and the changes that took place as a result of the new condition that prevailed over the family are evident.

3rd family of children with ASD: "I'm the mother of an autistic child, I've accepted it!"

Mother, 38, female, divorced, complete higher education. She had a degree in business administration, but never practiced it. She is currently a surgical instrument operator. She lives with her daughter. She became pregnant at the age of 25 and reported the following events during her pregnancy:

So, there were a lot of ups and downs, it wasn't a hundred percent pregnancy, you know, because there was the depression, the separation and everything, and it got worse. Because to this day I don't feel cramps during all my periods, I don't feel cramps at all, and during childbirth it was the same, I didn't feel cramps. they kept me in hospital.

She told us about the long hours of labor, saying that because of this, her daughter was born with a lack of oxygen to the brain:

"She was born with a lack of oxygen to the brain". He explained that after the birth of his daughter, no developmental changes were noticed, just the fact that she didn't interact much with people, without much reaction, but at 6 months these signs started to become more evident, bringing about changes: "He was very big and soft and people thought he was special. That's when she started at six months. It's difficult because shouting draws attention and I didn't know how to react".

She said that in addition to autism, her daughter had been diagnosed with several conditions, all with a high degree of dependency:

She was diagnosed with severe mental retardation and deaf and dumb imperatives. She was also diagnosed with keratoconus. Another struggle was that as a result of this process, she has lost 100% of the

sight in her right eye and is on the transplant list. Not to mention her severe autism.

Even with all these obstacles, the mother said that her life didn't come to a standstill and she carried on with her daily life in the same way:

So accept her the way she is and I never put up the obstacle of oh, because I'm not going to leave because of her. I think I really realized what it was like to be the mother of an autistic child, right? So for me, I don't have it today, but now I'm told that your mother is a special child, it never stops being a struggle, because every day there's a little problem.

4th family of children with ASD: "I found out my son was autistic thanks to my father watching a TV series"

Father, 36, male, divorced, completed high school, worked as a salesman, has a 10-year-old daughter and a 6-year-old son. He lives at home with his children and his father. Even though his wife doesn't live with him, he tells us about his life:

My wife's pregnancy was normal and peaceful, and my son received all the prenatal care. Everything that was requested during prenatal care was done. It was a normal birth.

He said that it was at the age of two that he began to notice signs in his son, signs that corresponded to ASD:

The discovery came more after two years, when he began to show different signs in relation to our older daughter and her behavior, for example, he began to stack his toys and separate metal on one side from plastic on the other, arranging them differently on a shelf.

Before she was diagnosed, she said she didn't know anything about ASD, she felt afraid because she didn't know anything about it and wondered what it would be like to look after a child with ASD:

I didn't know what it was, so I started researching and began to find out what it was. As I got deeper into it, I drowned, because I saw here that it wasn't a disease that has a treatment, but a syndrome that has no cure, as the doctor explained.

In the same space between fear and not knowing what to do with his son who has been diagnosed with ASD, he asks himself several internal questions: I was digging a grave about it, I was scared, saying:

How am I going to deal with this? What's my life going to be like? I have no knowledge of a special child. How am I going to deal with it? I know of a special child. How am I going to deal with it?

In order to understand the world of ASD, he began to study the subject and participate more frequently in environments that talked about ASD:

I've been taking part in talks at a neighborhood school association, and one of the parents started explaining. We saw his case, he also has two children and other parents telling him how it is. And how the care is being taken in relation to all of this, so I was given that comfort, because... I thought I was alone listening to it all.

All these signs were noticed by the grandfather when he watched a series in which one of the characters was autistic:

My father, watching a series, saw that a child was autistic and he came in like this and said that his behavior was very similar to what he saw.

At the age of six, his son didn't speak, which became a worrying factor for the father because he didn't understand what his son was

feeling, but this issue started when he was diagnosed, because he thought his son was deaf and mute, but he realized that when he asked him to do something, he was able to do it, so this issue was dismissed:

Today he's six years old and has never spoken and we think he will one day, but will he become like other children and only speak in adulthood? He doesn't speak, he's non-verbal. I understand that he's not deaf and dumb, because if I say, "Oh, put your slippers on," he goes and puts his slippers on, along with today's shirt. If there's going to be an event with him, he already knows what it is, so he understands and I understand that he's not deaf.

He said that even though he had a son with ASD, he was a little afraid, but at the same time he said that it had changed his life completely:

So... autism has also changed our lives, because I've started to look at life in a different way and understand other people's sides of things. It's because it's not easy to arrive like this.

Even with all the difficulties, he still has such a strong bond with his son that even if his son cries, he cries too.

You're surprised by him, you're moved by him and you cry with him, because he's very real. When he wants to cry, I cry too, but when he wants to smile he's very happy and I want to experience those moments. With all the difficulties that exist, the father reported that his daughter's relationship with her brother is very healthy and loving; even though she is 10 years old, she already understands the context of ASD, accepts and defends her brother and at the same time loves him: A ten-year-old child, she was saying... that her brother is everything to her in his own way! He bit me, but I didn't hit him because I know he didn't mean it.

5th family of children with ASD: "I discovered autism when I was in São Paulo, I felt unprepared"

Mother, 38, divorced, complete high school education, worked as a day laborer in family homes. She lived with her two children, a 10-year-old and an 8-year-old. She told us about her life, from conception to the present day:

My pregnancy went smoothly, without many things to complain about, I didn't feel much pain, I didn't feel sick. My son was born weighing three kilos and five hundred grams, all beautiful, and he cried out, which was the most beautiful thing in the world!

After her pregnancy and birth, she had to go to São Paulo in search of new opportunities, and the whole family went along for the ride. Over the years, her son grew up, and with him the signs began to appear, until she began to pay more attention to them:

I had to go to São Paulo to try a new life. I was working as a cleaner in São Paulo and it was all an experience. The signs of autism came at a time in my life when everything was going backwards and I was very desperate. I didn't know what it was, I was desperate.

She said that she went to various places in the area and no one could say exactly what her son had, some just said that it was a phase of the child and that it would soon pass, but she was still upset:

I couldn't get any guidance anywhere I went. They didn't tell me the right things, some even said it was just a childish phase and that it would soon pass.

She said that when she noticed the signs of ASD, her husband didn't take too kindly to having an autistic child and decided to move away, leaving her and their children alone:

As soon as my son showed signs of not interacting socially, my husband withdrew until we divorced and I was left alone with my son.

Speaking of the signs she was able to identify in her son, she explained.

And my son began to organize his toys in the same way, always in the same position, always with the same details, and even then he couldn't communicate.

Even though her husband was no longer present, she decided to go to professionals to find out the real condition of her son:

I looked for various professionals and that's when I found myself. They recommended me and I went to Mackenzie at the time and it was there that they really closed the diagnosis. My son, he also has a bit of genius and he can talk about all the subway lines that exist from the junction, where he stops, where he arrives, where he crosses.

After being diagnosed with ASD, she realized that her life had changed and that from that moment on she would have to change her whole life for the sake of her son:

But as I had to dedicate my life to my son, all the guidelines, knowing that your child has autism is not an easy thing, but at the same time it becomes a light thing, because now you know what you have and how you can help this child who depends on you one hundred percent. So I completely gave up my life to look after my son.

Still living in São Paulo, she said that she needed to return to Alagoas because the cost of living there was too high, so she decided to go back:

But as the city is very expensive, I had to return here to the state, together with my family, and today we offer, through the free ways I find, all the structure for my son's development.

Discussion

Changes in the family context are expected when there is a child with ASD due to their behaviour, which is characterized, according to the DSM-5, by impairment in social interaction skills, communication and behaviour, as well as interest in activities with restricted and repetitive patterns.¹⁰ It is a challenge for the family due to the need for organization in the face of intense dedication and care for the child with the disorder.¹¹ The signs of ASD are recognized between 12 and 24 months of the child's life. Faced with perceptions of the autistic child's behavioral differences, family members turn to various professionals, based on the hypothesis of various disorders. Families of children diagnosed with ASD experience a dynamic process, in which the members mobilize, taking on active roles in the face of signs, diagnosis and care, so that the interpretation of the situations experienced, as well as the interactions with the child, directs the actions taken by them.¹²

In the stories told by the families, it can be seen that this dynamic process has taken place, and changes have been evident both to them and to outsiders, in this case other family members, for example; in family 1, interaction with other members has been affected, leading to social distancing. Families have to search for a diagnosis of ASD with various professionals, and this can take months and sometimes even years (family 1), given the complexity of making a diagnosis. Through the narratives, the factors of acceptance after identifying the signs make family life more intemperate, issues such as fear, denial and frustration make the search more stressful and tiring, observed in families 1, 2 and 3.

Santos¹³ in his study points out that the lack of knowledge or misconceptions about autism highlights the excess of information about ASD for society, especially for the lay population, who may live with ASD on a daily basis, which can even lead to a lack of concrete information about it. In order for autistic people to be recognized as citizens, it is necessary for the concept, characteristics and forms of treatment to be known by everyone, making it easier for families, specialists and society to accept them, so that they receive the necessary support from public health policies for their cognitive, personal and social development. Several factors were found and highlighted, including the fact that most families feel fragile when they receive the diagnosis and are slow to believe that their child has any of these specificities. However, parents/caregivers realize even before the diagnosis that their children behave differently from other children, which is why they seek medical evaluation.

The changes that have taken place in the family structure in contemporary society highlight the entry of women into the labor market, their assumption of a more active role in social life and their greater contribution to the family's economic subsistence. Consequently, the number of families in which both parents work has increased, leading to a greater need for family tasks to be redistributed.¹⁴ When autism is diagnosed, the family becomes socially isolated and distant from other family members, the family feels uncomfortable with the child's behavior in places with loud noises, and other family members may not accept the diagnosis because they think the behavior is related to the child's personality, thus avoiding closer relationships.^{12,15,16}

Final considerations

The study with the families gave rise to reflections that made it possible to understand the particularities surrounding the universe of children with ASD in the face of diverse needs and contexts. Through care that is culturally congruent with the client's real needs, it is possible to achieve a state of well-being, as well as facilitate identity reformulation and behavioral change, which in turn can prevent the chronicity of illnesses. From what was collected during the interviews, it was possible to perceive the needs that often go through situations that are challenging to achieve, taking into account the finding of ASD. Among many, the most striking was the search for greater accessibility; the effectiveness of public policies aimed at families of children with ASD; the increase in skills, especially on the part of nursing staff, in tracking and identifying signs of autism itself. The families' daily lives changed considerably after the discovery of ASD, all feelings were amplified, causing a range of situations, from marital separation to distancing from the child. This is why continuity of services/support is a fundamental element in the transition process. This continuity must be safeguarded through careful and rigorous preparation for the transition, based on formalized cooperation models that include visits, meetings and other encounters.

Acknowledgments

None.

Conflicts of interest

The author declares that there is no conflicts of interest.

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