



RESEARCH ARTICLE

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## MATERNAL EXPERIENCES WITH AUTISM AND ITS IMPLICATIONS TO NURSING CARE

**\*<sup>1</sup>Luiza Alves dos Santos, <sup>2</sup>Nyagra Ribeiro de Araújo, <sup>3</sup>Aretha Feitosa de Araújo, <sup>4</sup>Maria Maiza Barros, <sup>4</sup>Myrla Alves de Oliveira, <sup>5</sup>Cícera Beatriz Baratta Pinheiro, <sup>3</sup>Leidy Dayane Paiva de Abreu, <sup>2</sup>Sabrina Martins Alves and <sup>3</sup>Karlla da Conceição Bezerra Brito Veras**

<sup>1</sup>Nurse. Regional University of Cariri - URCA (CE), Brazil

<sup>2</sup>Nurse. Graduate student in Health Sciences, Faculty of Medicine of ABC Paulista (FMABC), São Paulo, Brazil

<sup>3,7,9</sup>Nurse. Graduate student in the Graduate Program in Clinical Care in Nursing and Health of the State University of Ceará (UECE), Fortaleza (CE), Brazil

<sup>4,5</sup>Psychologist at the Federal Institute of Ceará. Crato, Brazil

<sup>6</sup>Nurse. Master in Public Health from the State University of Ceará (UECE), Fortaleza (CE), Brazil

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### ABSTRACT

Descriptive and qualitative study that aimed to describe the experiences of mothers with autism and its implications for nursing care. Semi-structured interviews were conducted with 09 mothers of children with autism from March to May 2016, at the Child and Youth Psychosocial Care Center of Iguatu, Ceará. The data were analyzed in light of the technique of the discourse of the collective subject. The results showed that adapting to autism is a tiresome and difficult, and sometimes painful task. For many mothers to have an autistic child means renouncing their professional and social life. Support, guidance, counseling through child support institutions and therapeutic services appear as important options in autistic care, but mothers also need support and care, and nursing can assist in this process through evaluation and of communication, to assist the core child, mother and family.

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## INTRODUCTION

The expectation of a child represents a sublime moment for the family, generating feelings of joy and anxiety, especially for the mother who undergoes numerous physical, psychic and emotional changes that lead her to create fantasies, expectations and even to foresee all the physical structure of the child (TORRES *et al.*, 2012). When the child is born, the family goes through a reorganization, which becomes dramatic when the child does not develop as expected and presents difficulties in the early interaction with the environment, family and society. This is especially true when these situations are caused or accentuated by organic, genetic or acquired problems such as autism (RODRIGUES; FONSECA; SILVA, 2008). Children with autism show little flexibility to routine changes and a limited and circular repertoire of interests and activities.

\*Corresponding author: Luiza Alves dos Santos,  
Nurse. Regional University of Cariri - URCA (CE), Brazil

Despite of this, the family idealizes a routine and a series of appearances of daily functioning that the child sometimes fails to reach (MARTINS; GÓES, 2013). Autism is a complex syndrome that has several characteristics. Although it was described more than 70 years ago, it still causes concern among physicians and researchers who have studied the topic deeper and deeper. But, apart from its clinical form, little is known (ANDRADE, 2012). Therefore, the interpersonal relationships of these children can be difficult depending on the level of development displayed. As they have a chronic condition, they face significant difficulties in carrying out common tasks, increasing the demand for care and, consequently, the level of dependency on parents and/or caregivers. There are varied difficulties, changes and needs that can be felt by the family, which has, at its core, children with autism. This fact leads to a set of experiences, which affect the family in general, both positively and negatively (NOGUEIRA; RIO, 2011). Mothers are the ones who, among

the members of the family, can be the most emotionally and socially affected, as they have to face the deconstruction of the child imagined before and during pregnancy. In this sense, they are more likely to experience feelings that can cause problems in the mother-child relationship, including sadness, frustration, ambivalence, and denial. Taking the unexpected role of the mother of a child with atypical development can raise stress levels and generate additional overloads in the social, psychological and financial fields (TORRES *et al.*, 2012). Thus, people with autism and their families should be a target of care. To this end, they must have access to professionals and reference services in the public network. These are interconnected and provide support and subsidies for patients, mothers and families, favoring a better follow-up for autistic patients and the adaptation of families to this scenario (BRASIL, 2015). In this context, the Psychosocial Care Center (CAPS) is a reference service for Autism Spectrum Disorder (ASD) and works in conjunction with the Family Health Strategy (FHS) and the points of urgency care, providing subsidies and acting directly in severe cases, being also responsible for the care in the urgency rooms. Care for patients with ASD should involve a multidisciplinary team composed of: psychotherapeutic nurses, speech therapists, psychiatrists, occupational therapists, psycho educators, among others. In this sense, the focus of this study was on mothers of children diagnosed with autism. The study sought to understand the feelings and identify what things that changed in their everyday lives in the face of this reality, as well as verify the professional support they receive. From this perspective, the present study aimed to describe the experiences of mothers with autism and its implications for nursing care.

## MATERIALS AND METHODS

This is a descriptive study with qualitative approach describing and working with the experience and the nature of meanings, motives, aspirations, attitudes and feelings. The study was carried out from March to May 2016, with nine mothers of children with medical diagnosis of autism followed-up at the Child and Youth Psychosocial Care Center (CAPSi). The chosen service is located in the municipality of Iguatu, Ceará, and is a reference for 10 municipalities in the Center-South Region of the State. Mothers over the age of 18 who were in the follow-up of children from the beginning of the diagnosis and treatment, who were present at said institution during the period of collection, and mothers whose child was less than twelve years of age participated in the study. This age was chosen because the Statute of the Child and Adolescent (SCA) considers that children are those who are in the age range up to twelve incomplete years. Mothers of children diagnosed with other pathologies associated with autism were excluded from the study. The research was carried out in two moments; in the first moment the demands were identified through medical records. Children with diagnoses of autism assisted in the referred center, who were accompanied by their mothers, and who fit the inclusion/exclusion criteria, were surveyed. In the second moment, the researchers went to the study scenario and used as a data collection instrument a semi-structured form that was applied to the mothers through an interview recorded in a portable audio micro recorder to ensure the correct transcription of the information. The data were organized and analyzed with support in the technique of discourse of the collective subject (DCS). This technique allows us to know what a collective group thinks about a subject within a single discourse and makes clear the set of representations that

confirms an imaginary datum. The procedures for analysis began with exhaustive readings of the material until the primary ideas of the analysis plan were identified. Then, the key expressions and central ideas of each discourse were selected, and then synthesized in the discourse of the collective subject. This research complied with the recommendations of Resolution n° 466/12 of the National Research Ethics Commission (CONEP). The project was approved by the Research Ethics Committee (REC) of the Regional University of Cariri (URCA) under CAAE n° 53035916.0.0000.5055/ Opinion number 1,532,515 and the subjects were duly informed and clarified about the objectives of the research by means of the Informed Consent Term.

## RESULTS AND DISCUSSIONS

**Characterization of subjects:** Among the women involved, there was a predominance of married people (66.67%), with complete high school (66.67%), only one child (55.56%) and age ranging from 30 to 35 years (55.56%). The age of the mothers may be one of the factors that increase the risk of having a baby suffering from autism. Parellada *et al.* (2014) cites maternal age as one of the elements to be investigated to discover the cause of the onset of autism. Concerning the occupation, of the nine mothers interviewed, only 3 (33.33%) had fixed employment, 2 (22.22%) worked as autonomous workers, and 4 (44.45%) did not work. This situation corroborates Cuvero's (2008) where mothers reported that they had abandoned their jobs to care for their children. Thus, there was an impact on their social and professional lives. Thus, the fact that some mothers do not work may be the result of dedicating their time almost exclusively to their children, perhaps because they do not have anyone to look after them in their absence or because of the lack of resources to pay a helper because the predominant family income is one minimum wage. However, there are those who have incomes below a minimum wage and none of them exceeds two minimum wages. Before the first question, two DCSs emerged (discourses of the collective subject). They are expressed in the central idea 1 and 2, and they revealed the changes that took place in the lives of mothers after the diagnosis of autism, which are related to lack of time, suffering, considering their inexperience and inability to provide maternal care in the new and unknown world of autism. See Table 01.

**Table 1. Central ideas 1 and 2 and the discourse of the collective subject in response to the question 1. CAPSi, Iguatu-CE, 2016**

**Question 01: What has changed in your life after your child was diagnosed with autism?**

**CI 1:** Search for new knowledge

**DCS 1:** "I came to see reality with different eyes when I discovered that my son is autistic [...], I had to try to understand, my head opened more in relation to autism and other diseases that he could have; [...] I needed to get knowledge so that I could take care of him, talk to him, dedicate myself to him and have a lot of patience".

**CI 2:** Changes in daily life and lack of time

**DCS 2:** "My time now is more dedicated to him [...], it was harder for me to leave home, work, go to church, because he needs a lot of attention. I take care of him alone [...], I have to always run from one place to another to do therapy, consultations and treatment, there is no time for anything else. It gets very tiring [...], it has changed the routine, the economic issue, housing, leisure, because there are certain places and moments that you cannot go with him, and then I do not go".

It was evident the discourses of the mothers that these characteristics affected not only the autistic children but also the lives of their mothers. They had to adapt to this new life, so as to be able to best assist in the integral development of their children. In this sense, most of the demands end up on the mothers and they are the ones that get most involved in the role of caregiver. It is not rare to see mothers assuming full responsibility for the emotional, physical, and financial care (CARVALHO *et al.*, 2010). In this way, the transformations and adjustments that families of autistic children have to face in their daily life are innumerable. Difficulties occur in all families regardless of whether they have children with any special needs or not. The DCS in the case of the second question unveiled the central idea of positive feelings and overcoming, even in the face of the discovery of autism and the challenges involved in this condition. In spite of this, the second central idea brings the negative feelings of sadness and indignation experienced also by these mothers. See Table 02.

**Table 2. Central ideas 1 and 2 and the discourse of the collective subject in response to the question 2. CAPSi, Iguatu-CE, 2016**

**Question 02: What are your feelings about your autistic child?**

**CI1:** Positive feelings and overcoming

**DCS 1:** "We love the same way, today I feel love, a lot of love for him and I know he can change, he just needs more attention [...]; At first I was worried because I did not know anything about autism, I did not know what to do, but when the first impact happened, I tried to better understand autism so I could help him. Today I see everything in a different way; I think the feeling now is of love.

**CI2:** Negative feelings

**DCS 2:** I felt a lot of sadness, guilt, frustration; I was very distressed when I discovered; [...] I think even I felt sorry for him, I wanted the thing to be different [...]; At the first consultation the physician said that it could be autism, I was very sad, I cried, and every consultation I had that hope that the problem was not turn out to be autism [...]. It was a bad feeling because no one expects that, but what can we do? now we have to take care".

Discovering the child as autistic can bring many uncertainties to the lives of the mothers, but also some relief for the possibility of seeking a suitable treatment for the child. However, the contrast between the ideal child and the real child becomes greater by the thought that because of his limitations, the child will probably not meet the idealized expectations since birth. According to Núñez (2007), when the limitations of the child are confirmed, parents develop feelings such as concern, disappointment, anxiety and guilt. The study by Welter *et al.* (2008) also suggests that the most common feelings in mothers who have children with a particular disability are uncertainty, sadness, guilt and nonconformity.

It is also observed that in the beginning, mothers tend to deny the diagnosis as a means of defense, although temporary, and later replace the denial by acceptance, although partially. Moreover, for certain families, acceptance is a constant process that can never be completely finished (OLIVEIRA *et al.*, 2014). The discourses of mothers indicated that the first feelings when they learned that their children were autistic were negative. However, although mothers do not fail to have these feelings, over time they begin to look at autism with a different perspective, realizing that life with autism exists and that their children need love, care, and patience. In the third question, three central ideas emerged. They revealed that mothers face many challenges in caring for and treating their autistic children. The challenges included not only the clinical picture of the disease itself, which affects communication and

learning, but also ignorance of professionals about autism and also lack of financial resources, as shown in Table 03.

**Table 3. Central ideas 1, 2 and 3 and the discourse of the collective subject in response to the question 3. CAPSi, Iguatu-CE, 2016**

**Question 3: What challenges do you face in the care and treatment of your child?**

**CI1:** Difficulties in communication and learning

**DCS 1:** "After realizing that he would not speak I looked for the FHP (Family Health Program) [...]; It's a challenge every day to find a way to make him understand what I say and I understand what he wants. At that time I have to unfold myself to discover and make his wish; [...] thus, there are many challenges, such as seeing him learn, seeing the changes in his behavior, all this leads me to believe that I am winning and that one day he will become an independent person [...] for everything I've read about autism I know it can require much effort, but it's not impossible".

**CI2:** Lack of extensive knowledge on the part of professionals

**DCS 2:** "Autism is still something misunderstood by the professionals, some say one thing, others say another and that confuses people's minds [...]; We have to study and research on the subject".

**CI3:** Lack of own resources for treatment

**DCS 3:** "Adjusting my life to hers and my financial resources is very difficult [...]; For the treatment has to be always followed-up, then we end up spending a lot more and I cannot even get a job".

Mental illnesses usually remain for a long time and are recurrent. They also bring a concept of fragility and inaptitude attributed by society. This ends up becoming the cause of overload, be it in the physical, emotional or economic area and also generates many changes in the evolution of the family, affecting several areas in social life, health, professional competence and other areas (CAVALHERI, 2010). Despite stressful, these changes become necessary to improve adaptation to the specific limitations and needs of the autistic child. It can be emphasized that it is mainly in the family environment that the difficulties are exposed by challenging the parents to play their role as educators of the children, making them participate actively in the current society, which emphasizes aspects such as effectiveness and efficiency (SANTANA; RABINOVICH, 2012). According to Jerusalinsky (2007), even greater difficulties arise when the child starts to integrate into society, becoming a period of conflict, since in the first attempts, in places where other children are, social rejection is noticeable in the view of parents. Another difficulty that has also been widely reported by mothers is the lack of information about autism that complicates both its diagnosis and treatment. According to Nogueira and Rio (2011), the lack of information about the disease is one of the biggest complaints exposed by relatives. According to researchers, it is not always that data on the subject are available and how to deal with the symptoms, thus preventing the family's understanding of autism.

However, there is not only a lack of information in research sources (such as the internet, books ...), but mainly lack of knowledge of professionals for the diagnosis and continuous care of autistic patients. This causes, consequently, a delay in treatment. Data obtained in the study by Visani and Rabello (2012) revealed that although there are methods for early detection of autism, methods that make it possible to identify traits of this disorder in babies from the age of three months, the formal diagnosis only occurred when the child was two years old in 21.4% of those surveyed; three years old in 14.3%; four years old in 28.6%; five years old in 18.6%; and six years old in 7.1% of the respondents. This delay in diagnosis makes the mothers' lives even more stressful because they have no idea how to help their children develop.

Besides delayed diagnosis and other sources of stress, the family, especially the mothers, have to deal with financial burdens that they are unable to sustain and that are necessary to treat their children, such as educational services and specialized professionals, bringing even more problems for the families, particularly those with low purchasing power. When questioned about the units and professionals that assisted the mothers in the care and treatment of their child, two central ideas emerged. One was related to the multiprofessional treatment that the child needs and another related to the services available in Primary Health Care and in society, such as schools. See Table 04.

**Table 4. Central ideas 1, 2 and 3 and the discourse of the collective subject, in response to the question 4. CAPSi, Iguatu-CE, 2016**

**Question 4: Which are the units, entities, and professionals that provide support to give you greater capacity to care for and treat your child?**

CI1: Multiprofessional team

DCS1: "To care for and treat my son with autism better, I count on the help of a very large team of professionals [...] a psychologist, occupational therapist, speech therapist, nurse, neuro-pediatrician and psychiatrist.

CI 2: Support services

DCS2: "After the confirmed diagnosis, I count with the help of the CAPSi [...] professionals, the school he attends... and the FHP."

According to Nogueira and Rio (2011), the concerns and anxieties caused by this diagnosis are many for these families. This also arises concerns that are mostly related to what public and/or private institutions can do to safeguard the rights of their children and collaborate to the maximum for their full development. Considering these aspects, it is understood that the sectors of social interaction, behavior and communication are directly associated in human development since birth. Taking into account that individuals with autism exhibit delays in these sectors, it is up to the professionals who work with them to adopt methods that encompass the acquisition of capacities that are requirements for other abilities to materialize. In this perspective, Lemos, Salomão and Agripino-Ramos (2014) emphasize the school as one of the places that help children's development, because it offers moments of interaction with other children and because of the relevant role of teachers, whose interventions help in the acquisition of skills by the children. One of the major advances in the field of mental health was the change in the form of patient care, leaving behind the normative, centralized concept. The Psychosocial Care Center for Children and Adolescents (CAPSi) is the highlight of this new form of care (SILVA, 2012). According to Administrative Rule 336/2002, the CAPSi is responsible for promoting comprehensive care for children and adolescents with mental disorders, according to their need, as well as for their families. The CAPSi also has the task of establishing the network of care, adding the various organs of social adherence, mainly, the families (REIS *et al.*, 2010). The Family Health Strategy (FHS) is a strategy of the Federal Government in the field of primary health care implemented in the daily life of the community, in order to become closer to the families. Its purpose is to ease the patients' psychic sufferings in mental health, in the expectation of improving the quality of life of patients, especially in the embracement, bonding and in the family (MENEZES; MELO, 2010).

Through the speeches, although schools and the Family Health Strategy were mentioned, the relevance of Casa Azul (name given to the Psychosocial Care Center for Children and Adolescents of Iguatu) was clearly observed as element of support for mothers to better treat and care for their autistic child.

CAPSi professionals seek to act in an interdisciplinary way, in order to share the knowledge among them, in order to discover more appropriate tactics to provide assistance to adolescents and their families (SILVA, 2012).

**Experiences of Mothers Facing Autism and their Implications for Nursing Care:**

And it is in this context that nursing has room for action, both in terms of caring for the children and caring for the families that, in this period, are vulnerable, needing support and guidance on what course to take. Daily routine with autistic children may be complex depending on the level of development exhibited. According to Carniel, Saldanha and Fensterseifer (2010), health professionals, and especially the nursing team, considering that nurses are the professionals who stay longer with the children, should be trained. In the care for families, nurses play the role of educators, guiding them about autism, based on a trusting relationship, discussing ways and possibilities to help the children develop. In addition, nurses need to plan and determine a strategy of care for the families. Regarding the children, nurses can play the role of socializing agent, promoting the insertion of the autistic children in society (CARNIEL; SALDANHA; FENSTERSEIFER, 2010). It is common for professionals to seek together with the family or other members who are active in the social environment a way of dividing the tasks assigned to them. This proves the deficiency in the service provided to the user where "the individualization processes often happens through responsabilization of intermediary relatives" (SILVA, 2009).

Thus, it is essential to understand the vision of nursing professionals about the subject, seeking to detect flaws or skills of these professionals, with the purpose of getting more and more effective in protecting the autistic children and their families. However, we can see that, in practice, this does not happen in the way it is perceived in the speeches; there are few professionals who specialize in supporting children with autism and their families, and even those who are "trained" demonstrate limited knowledge about autism. Thus, Barbosa *et al.* (2012) reported that of all the health professionals responsible for this care, nurses have the important role of humanization. This humanized aspect of caregivers will result in health professionals being able to see evidence that, within their capabilities, they are able to help improving the quality of life and well-being of those under their responsibility.

**Conclusion**

The results gathered in this study show that adapting to autism is, for the family and especially for mothers, a tiresome, difficult, and sometimes painful task. When a child is planned, a healthy and perfect child is desired, and the child is never expected to be born with any problem whatsoever. The moment the idealized child begins to exhibit characteristics, such as difficulty or delay in speaking, and problems in establishing relationships of affection, the imagined dreams about this child fall to the ground and the family is confronted with a new reality, which may make the family lose balance and then establish a new organization. With this, it is perceived

that autism leads the family environment to suffer ruptures by interrupting the usual social practices, modifying the emotional climate where the family lives. This change can be seen in the reports of the mothers, demonstrated by the most different types of feelings: guilt, sadness, frustration, anguish, acceptance, and love. Difficulty and long paths taken by mothers to obtain a definition of the diagnosis were also observed. After confirmation of autism, new disturbances arise in the family context in the face of doubts regarding expectations for the lives of their children. It is from that period that children become fragile by their limitations, and the mothers start to devote their time almost entirely to the care of their autistic child, and this can lead to an overload. Thus, the social isolation of these mothers was another important point. Some of the mothers who participated in the research reported that, probably because of their attempts to spare their children from indiscreet looks, lack of tolerance on the part of society and prejudice, or even because they felt it necessary to take children to medical follow-up, they were isolated in their homes, with rare occasions for resting outside this environment. Thus, questions arise about this form of life of mothers. It becomes fundamental to reflect on the extent to which this overload of dedication is favorable to the health of the child, the woman, or even other family members such as the spouse and other children. Thus, while it is stressful and difficult for families, especially mothers, to care for their autistic children, it is of utmost importance that all of them live together in a harmonious place that can provide quality development for all family members. Thus, it is necessary to establish a strong and prolonged relationship, because this relationship is necessary for the child to feel safe and protected, which is of great relevance for emotional bonding and guidance to improve the child's affective, cognitive and social development. In the case of questions regarding the experiences of mothers, it is necessary to see not only the autistic children, but also their families, especially the mothers, considering that they are the ones who assume most of the burden with regard to the children in the basic care of daily life.

Consequently, the services for these children and their families need to be based on the needs of each child and their families, in which they have the decision-making role and decide how they will help in the treatment of the child, that is, even if the intervention has a general curriculum, the daily routines and activities can be customized, making them individualized and adequate for each family. In this perspective, counseling, social support, through child support institutions, and therapeutic services appear as options to assist family members to deal with autism. With this, health professionals, and therefore nurses, need to understand that they have an essential position, through evaluation and communication, to help the autistic children in the best possible way, besides being in charge of the development of the personnel trained to confirm the diagnosis and start treatment. Finally, it is emphasized that the concerns and questions about the experience of mothers who have children with autism are not concluded with this research. The importance of future questions about autism through other aspects, not just related to mothers, is emphasized. As a proposal for other studies, research is needed about parents, and about how and in what intensity the conjugal relationship is affected when a child with a diagnosis of autism is born. There is also a need to build a more concrete knowledge on the part of nursing with the intention of consolidating the role of nurses in this context, and thus to

establish a more effective care, both for autistic children and their families. In this way, a humanized care is necessary, motivated by the difficulty and the effect that the diagnosis causes to families, as well as the need to be assisted by a dedicated and trained professionals who transmit confidence and optimism to all who live with the child.

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