

# EXPERIENCES OF PARENTS AND / OR CAREGIVERS OF AUTISTIC CHILDREN IN A PSYCHOLOGICAL SERVICE

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## VIVÊNCIAS DE PAIS E/OU CUIDADORES DE CRIANÇAS COM AUTISMO EM UM SERVIÇO DE PLANTÃO PSICOLÓGICO

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## VIVENCIAS DE LOS PADRES Y/O CUIDADORES DE NIÑOS CON AUTISMO EN UN SERVICIO DE GUARDIA PSICOLÓGICO

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**Objective:** to reveal the experiences of parents and / or caregivers of children with autism in a Psychological Service. **Method:** a descriptive, qualitative study with phenomenological inspiration, carried out with six parents / guardians by a nongovernmental organization located in Belém, Pará, Brazil. An interview and the versions of meaning were used for data collection. After analyzing the convergent points present in the versions of meaning, the analysis of the data was performed through the formation of three themes of meanings. **Results:** There was a formation of three themes of meaning: “mourning due to the diagnosis of autism”; “Difficulties with childcare” and “social isolation”. **Conclusion:** the stories and needs that led parents and / or caregivers of the children with autism to seek psychological services present singularities, however mourning due to the diagnosis of autism, difficulties with childcare and social isolation were the commonly shared themes.

**Descriptors:** Clinical psychology. Autistic disorder. Caregivers.

*Objetivo:* desvelar as vivências trazidas por pais e/ou cuidadores de crianças com autismo em um serviço de Plantão Psicológico. *Método:* estudo descritivo, qualitativo de inspiração fenomenológica, realizado com seis pais/cuidadores em uma Organização não Governamental localizada em Belém, Pará, Brasil. Para a coleta de dados, foi realizada entrevista e versão de sentido. A análise dos dados foi realizada por meio da formação de eixos de significados, após análise dos pontos convergentes presentes nas versões de sentido. *Resultados:* encontrou-se a formação de três eixos de significação, a saber: “luto diante do diagnóstico de autismo”; “dificuldades com os cuidados com a criança” e “isolamento social”. *Conclusão:* as histórias e demandas que levaram os pais e/ou cuidadores de crianças com autismo a procurar o plantão psicológico apresentaram singularidades, contudo o luto diante do diagnóstico, as dificuldades com os cuidados com as crianças e o isolamento social foram eixos comuns que compartilharam.

*Descriptores:* Psicología clínica. Transtorno autístico. Cuidadores.

*Objetivo:* desvelar las vivencias traídas por los padres y/o cuidadores de niños con autismo en un servicio de Guardia Psicológico. *Método:* estudio descriptivo, cualitativo, de inspiración fenomenológico, realizado con seis padres/cuidadores en una Organización no Gubernamental localizada en Belém, Pará, Brasil. Para la recolecta de datos, se realizaron entrevistas y la versión de sentido. El análisis de los datos fue realizado a través de la formación de ejes de significados, posterior al análisis de los puntos convergentes presentes en las versiones de sentido. *Resultados:*

*se detectó la formación de tres ejes de significados: “el luto frente al diagnóstico de autismo”; “las dificultades con los cuidados con el niño” y “el aislamiento social”. Conclusión: las historias y demandas que llevaron a los padres y/o cuidadores de niños con autismo a buscar el servicio de guardia psicológica, presentaron singularidades, sin embargo, el luto frente al diagnóstico, las dificultades con los cuidados con los niños y el aislamiento social, fueron ejes comunes presentes entre los entrevistados.*

*Descriptores: Psicología clínica. Trastorno autista. Cuidadores.*

## Introduction

Autism is a complex disorder that affects the child's development and can result in intense distress for their parents and other family members. It is estimated that about 10% to 20% of children and adolescents suffer from mental disorders, and that about 3% to 4% require intensive treatment. In this group, the autism spectrum disorder is one of the most frequent<sup>(1)</sup>. There is a 0.5% prevalence of autism in the population, with the male sex being four to five times affected than the female sex<sup>(2)</sup>.

Regarding its implications, it is known that autism compromises the child development process and is classified, according to the Diagnostic and Statistical Manual of Mental Disorders<sup>(3)</sup>, as a neurodevelopmental disorder, because it affects important developmental areas. Such disorders usually manifest themselves in the early stages of development, often before the child enters school. The autistic spectrum is characterized by deficits in communication, social interaction and repetitive patterns (behavioral, interests or activities).

These changes can occur in varying ways, at different degrees of impairment, thus constituting a continuum or spectrum of disorders. In the area of communication, it is possible to notice different nuances, from the absence of the speech to the presence of speech with alterations in the communicative function. In social interaction, there is a continuum that begins with isolation and goes to the presence of social interaction, however performed inappropriately. Behavior patterns may be mild to severe in intensity, restricted and repetitive<sup>(4)</sup>.

The treatment of a child with autism is long and its progress depends on several factors,

such as the degree of mental impairment and therapeutic follow-up. In addition, “[...] the way in which the family reacts to the treatment of the child will be decisive in the evolution and recommencement of their development”<sup>(5:322)</sup>. The family will sometimes have to review their plans due to the child's autism.

Being a parent of a child with autism is not easy. It requires dealing with the unexpected. To be parents of these children is “[...] to embark on a complex experience, fraught with difficulties and extreme responsibilities, for the child may be partially or totally dependent on the parents”<sup>(6:275)</sup>.

Each parent, mother, or guardian who performs these functions experiences, in their own way, how to act when faced with the great challenge of caring for an autistic child. There are some factors that are determinant in family adaptation to autism: “[...] family functioning modes, intra- and extra-family communication patterns, quality of health systems and beliefs about health”<sup>(2:135)</sup>. Besides these, “[...] the individual characteristics, the challenges imposed by the disease, coping strategies and the social support network greatly contribute”<sup>(2:135)</sup>.

In this context, caring for those who take care of these children is fundamental, since the family is the first relationship context of an individual. An autistic child affects the whole family. Likewise, the child is affected by the way autism is visualized by the family to which they belong. That is, “[...] the participation of each member, with its particularities, affects others as well as it is affected by them in a interdependent relationship. Thus, every change exerts influence on each member individually and on the system as a whole”<sup>(2:134)</sup>.

Understanding the experiences of these parents / caregivers provides a solid basis for various professionals, supporting specific actions for this audience, that meet their needs and provide better quality of life. Therefore, the objective of this study is to reveal the experiences of parents and / or caregivers of autistic children in a Psychological Service.

## Method

A qualitative, phenomenological study performed in a psychological service of a non-governmental organization (NGO) in the city Belém, Pará, Brazil. This NGO is an institution created by parents of autistic children, whose purpose is to offer care to these children, in the areas of occupational therapy, psychology, speech therapy and pedagogy.

The Psychological Service was created with the purpose of responding to an emergency demand, of the caregivers of the children attended by the NGO. In this service, it is the responsibility of the professional to “[...] provide the client with a clearer view of themselves and their perspective on the problems they face. Thus, the confrontation of the problematic defines itself in its own process of duty and with the participation of both client and counsellor”<sup>(7:76)</sup>.

Data collection took place in a room designated for the psychological service, located near the coordination room of the institution and the parental waiting room and other treatment rooms. Therefore, it is an easily accessible place, equipped with a sofa, chair and computer. Data collection took place from September 2016 to June 2017.

Participants in the study were parents and/or caregivers of children who required assistance and were cared for in the Psychological Service during the data collection period, established in the study schedule, and who met the inclusion criteria of the study. Thus, the study population was composed of six participants; five mothers and one father.

Inclusion criteria were: to have sought care in the NGO Psychological Service; be a parent, or

other responsible person who acts as the primary caregiver of the child who is no older than 12 years of age and diagnosed with autism. The exclusion criterion was to be a father, mother and/or caregiver under the age of 18 years.

CNS Resolution No. 466/12 which deals with research involving human beings was followed for the development of this study. Data collection only occurred after approval from the Human Research Ethics Committee of the Health Sciences Institute of the *Universidade Federal do Pará* under Opinion n. 1,718,919.

Considering that this research involved a thematic that could generate feelings and situations of suffering, particular care was taken so that the personal exposure did not cause further psychological damage. The following aspects were observed: respect for the pain and suffering that the participants experienced in relation to the proposed theme; clear explanation of the research objectives; respect for the desire to participate or withdraw from the research; clarification on the possibility of withdrawing from the research if and when desired by the participant; guarantee of confidentiality regarding the identity of the research participants, patients or persons cited by them.

To honour the caregivers and ensure the anonymity of the participants they were given names of stars, as for the researchers, they are considered sources of light for the children.

Initially, the instrument chosen for data collection was a structured interview, used only to collect sociodemographic data, including data from the parent or guardian and the child. This interview consists of general data: name, age, sex, marital status and occupation. Afterwards, the child's information was requested: name, age, sex, diagnosis, length of time since receiving diagnosis and treatment.

After this step, care was provided to the caregiver in the psychological service, based on the Person-Centered Approach. This psychotherapeutic approach was developed by Carl Rogers, for which there are three fundamental conditions in the therapeutic relationship for the development of human potential in all people:

positive and unconditional positive regard, empathic understanding and congruence.

It was established that each employee could be attended up to 4 times in the psychological service. This criterion, according to the current practices in psychological services and the Person-Centered Approach, establishes that the difference in the amount of care for each caregiver will not influence the effectiveness of the data collection.

After the sessions, the professional wrote versions of meaning in response to the meeting. The versions of meaning are based on the phenomenology of the language of Merleau-Ponty (1908-1961) and Martin Buber (1878-1965). The versions of meaning are the researcher's free reports after the conclusion of a meeting<sup>(8)</sup>. This account is not intended to be true to the facts, but a "[...] living relationship, written or spoken immediately after the event, as a first word"<sup>(8:74)</sup>. Therefore, it is a discourse of the experience of a recently finished meeting or encounter.

Thus, immediately after attending the psychological service, the professional recorded versions of meanings after the meeting, with the objective of highlighting the meanings of the meeting. It is important to note that this production is a version of meaning and as such, is a version of who is writing.

The "meaning" of a relationship does not properly fit into any of the participants. In each, according to him, there is only the "secret accompaniment of the conversation itself", which is its subjective or psychological aspect. The sense of a relationship "is found only in this incarnate game between the two, in this his Among"<sup>(8:86)</sup>.

In this version, the theories of the researcher are put in suspension (phenomenological suspension). What is of interest in this production are the feelings and the meanings that come from the contact with the experiences of the collaborator, through the encounter between him/her and the researcher.

After producing the versions of meaning, the professional-researcher proceeded to read the produced text, aiming to visualize the experience in relation to the phenomenon in general. Subsequently, the versions of meaning

were analyzed, seeking to group expressions or phrases into groups of meaning (themes of meaning).

## Results and discussion

Through careful analysis of the versions of meaning, three categories of structures regarding the meaning of the experience of the consultations were observed; "Mourning due to the diagnosis of autism"; "Difficulties with child care"; and "Social isolation of families".

### *Mourning due to the diagnosis of autism*

Each family reacts differently and uniquely to the diagnosis of their child. "There is no exact or standard definition of family behavior, it depends on their relationship with the child and the expectations they have created for the child diagnosed with autism"<sup>(9:6)</sup>. Through the attendance at the psychological service, it was noticed that some parents were in a state of mourning due to their child being diagnosed as autistic.

Mourning occurs due to the loss of the healthy child that the parents expected, which triggers "[...] feelings of worthlessness because they have been chosen to live this painful experience"<sup>(10:231)</sup>. This loss also happens as a result of the dreams, ambitions and expectations that families must now abandon. In general, the diagnosis of autism causes countless successive losses to the parents.

*The diagnosis of his son brought deaths [...] I noticed that Aldebaran was very emotional. He contracted his muscles, made a great effort to stay calm, even if his tears insisted on trying to fall. I offered him a handkerchief, he said he did not usually use handkerchiefs. And he went on to say that he had always planned his life, that his son's arrival was no different. He dreamed of having a structured family, that his son would develop normally, but the diagnosis made many of his dreams die.*

"There are two types of death: concrete and symbolic. Concrete death is when a person dies and disappears forever. Symbolic death, or death in life, are ruptures that occur during the life of the human being"<sup>(11:90)</sup>. These ruptures may be as diverse as: "separations of couples, becoming ill (death of the healthy person), mutilation or

deformities acquired throughout life, mental illness [...] in human development, the child becomes an adolescent, which then becomes an adult, who then succumbs to old age<sup>(11:90)</sup>. In other words, there are several deaths that the individual can experience during life, including the death of the child that they imagined and expected.

A study<sup>(12)</sup> identified the five stages of loss or grief: denial, anger, bargaining, depression, and acceptance. The state of denial is characterized as a “[...] shock absorber after unexpected and shocking news, allowing the patient recover over a period of time, using other less radical measures<sup>(12:44)</sup>”.

The anger phase “[...] is the first contact with the real suffering [...] anger is the manifestation of all the pain that the possibility of acceptance of this reality provokes in the person as a possible reality<sup>(13:41)</sup>”. The third phase, the bargaining stage, is the moment when one feels useless when faced with reality and seeks the absolute through an attempt to negotiate with the sacred, whether through “promises, exchanges, pacts, etc.”<sup>(13:41)</sup>. The depression stage,

[...] is not melancholy in the psychopathological sense, as it is usually understood in psychology or psychiatry, but a moment of preparation, linked to future losses of loved persons, objects, projects and values and that serves as a facilitator for the acceptance of death. It is a kind of anticipatory mourning<sup>(13:41)</sup>.

Finally, in the acceptance stage, more elaboration about death and losses occurs.

Authors<sup>(9)</sup> compare the stages of mourning proposed by Kübler-Ross<sup>(12)</sup>, with the mourning experienced by parents of children diagnosed with autism. In this case, mourning is caused by the “loss of the idealized child”. Upon receiving the diagnosis of autism of your child, the family experiences

[...] the stages of mourning, in which they gradually begin to deconstruct the perfect ideal of the child they had imagined and expected. This loss represents something important to the family, because they did not expect that something different would happen, and it passes in a fragile and delicate way to the process of understanding loss<sup>(9:9)</sup>.

When a mother and father receives the news that their child has a significant difference in

their development, the reaction is one of shock because they are not prepared to be the father and mother of a child with difficulties<sup>(14)</sup>. Thus, “[...] discovering that this child has some form of disorder or deviation in their development, a situation of ‘mourning’ and ‘crisis’ is generated, as there is an imbalance between the necessary adjustment and the resources to deal with this problem situation<sup>(14:59)</sup>”.

A study<sup>(15)</sup> also highlights this issue when affirming that “[...] the impact of a diagnosis of a disease can cause the family to experience the same stages of mourning, including denial, which is an adaptation which people experience when they lose something longed for or meaningful<sup>(15:4)</sup>”.

In addition to these stages, another study<sup>(12)</sup> shows that there is a sixth stage: hope. After all, “[...] it is not in human nature to accept death without leaving an open door for hope<sup>(12:12)</sup>”. Upon observing the mourning process, which many parents of children with autism experience, it is possible to perceive the occurrence of a process of re-signification of experiences, and even of hope, allowing the parents to see life in another way. Thus, we can clearly observe hope in the passages of the versions of meaning;

*I feel that the phase that Adara has been going through, together with her husband, has made her reflect on her own mother. This figure who, for a long time of her life, was not well understood when they lived together, now that she is a woman and a mother, I see and feel that she understands her mother better [...]*

*She [Acru] did not know how to describe the dream well, but the feeling she had with him and that was revived in the session is that everything contributes to her growth and maturation.*

### *Difficulties in caring for the child*

Among the six people who were cared for, five women spoke about the difficulties they encountered while caring for their autistic child. They also highlighted how difficult it is to plan personal projects, such as taking a course and planning future goals while also caring for their child.

Due to its specificities, the autistic spectrum demands a lot from parents and / or caregivers. Many families feel incapable of facing the great

challenge of caring for a child with so many specific needs. The need for families to revise their future plans is a common reality<sup>(16)</sup>.

The nuclear family, consisting of a husband and other children, provides important support that helps the woman withstand the intense child care routine of the autistic child. Husbands mainly contribute with economic support, as women decide to renounce their professional careers<sup>(17:46)</sup>.

In this context, while many women stay in the home environment, taking care of their children, their husbands work to maintain the financial support.

Within the family environment, the woman is the primary caregiver of autistic children. As a result, women are more prone to developing stress caused by the excessive demands and workload related to the care of the child. This high level of stress can aggravate the physical and psychological health of these mothers. In addition, other factors are related to these overloads, such as: lack of marital support and excessive child care demand<sup>(16,18)</sup>. The recurrence of this issue is highlighted in a review article on the impact of autism on the family. Studies<sup>(16,19)</sup> highlight this recurrent issue “[...] mothers tend to be at higher risk of crisis and parental stress than fathers due to the demands of child care. According to these authors, there is a social expectation that mothers will take care of them and assume these activities more often than the fathers”<sup>(16:3)</sup>.

This is observed in the following passage of the version of meaning:

*He [Acrux] pointed out, with regret, that she could not even sit down to have lunch, because her daughter would not stop, so she always had to be at the ready [...] Acrux stressed that she also has a child diagnosed with autism and ADHD and that taking care of him alone is very difficult, especially when she has to walk with his two children at the same time [...] she pointed out how dangerous it was to deal with her physical exhaustion while caring for the children. Accidents could happen at home.*

*Besides caring for her son, Adara has a great desire to dedicate herself more to studies and she attends college. But she does many activities with her child. She even told me that she sleeps with the child to avoid waking her husband during the night.*

*Agena wants to do a lot of things, like a 3D drawing course, but she also feels impeded by the lack of time because she spends most of her time taking care of her*

*son [...] she doesn't want to be with her partner anymore, she does not like him anymore, but said that it was not simple to change course. Changing things involves having financial independence to achieve better things.*

Authors who analyzed the level of spousal support available to mothers and fathers of children with autism<sup>(16,20)</sup> found that mothers expect support from their spouses. Among the main types of desired support, the following were highlighted: “1) provide greater relief to the mother in relation to the care of the autistic children; 2) take greater disciplinary responsibility towards the child; 3) receive help from the fathers spontaneously, without the need for continued requests for help”<sup>(16:3)</sup>.

We perceived that these mothers have a great desire to share the responsibilities of raising their children with their partners. Many mothers stressed the importance of the fathers support in child care. At the same time, we noted the need for these mothers to share other demands, such as housekeeping and household expenses, as well as companionship and support.

*Adara came to the service mainly because of her difficulty in sharing the responsibilities and care of her son with her husband [...] However, she has come to realize that the best way to live with her partner is, in fact, the worst way because she is assuming the childcare obligations by herself*

*Canopus faces many difficulties with her ex-husband regarding financial care.*

*Arcturus said how difficult it is to lead a life without a family and to take care of a child with autism alone.*

*I felt that the husband was important to Acrux, but undoubtedly this importance is also due to the presence of the children that the two had. Acrux highlighted how much parents and mothers of children with autism worry about their deaths and what will happen to their children afterwards. In this context, she emphasized the importance of the figure of the husband to the children.*

Families of autistic children face many difficulties. These difficulties also permeate the feeling of social support experienced by these parents. One of the people who attended the service saw an opportunity for social appeal in our research. This person highlighted how difficult it is to carry out activities outside of the home if the mother / father has no one to mind the child. In this context, he spoke of the need for specialized places for autistic children,

who understand the children's' specificities and, above all, understand this world.

### *Social isolation of families*

Having an autistic child often caused families to be socially isolated because "[...] in an attempt to spare children from discriminatory looks or even lack of understanding on the part of other people, they end up being confined at home"<sup>(7:276)</sup>.

In addition, difficulties in accepting the diagnosis also permeate the view that society has about autism. We hear and realize, in the speeches of some parents, how accepting the diagnosis can be made difficult because of other people. A study that analysed the family's participation in the care of the child with autism is also identified: "[...] besides the difficulties due to the internal pressures since the birth of the child, there are also external pressures, as it is very difficult to live in society with any type of difference, prejudice is perhaps one of the principal conflicts experienced by the family"<sup>(18:11)</sup>.

*Both Adara and her husband still do not deal well with their son's diagnosis. This is also a factor that makes it difficult for Adara to go out in public [...] The family still experiences difficulties in accepting the diagnosis, and they withdraw from the world because of fear [...] Acceptance is the first step in the acceptance of the other.*

In this context, the child's contact with the outside world is important, however it is done in a cautious way. Many parents fear the reactions that their children will have to other people such as "[...] crisis, crying, crying, verbal or physical aggression, and even agitation. Parents fear that these behaviors may lead to social exposure and that they may experience feelings of shame, and sadness"<sup>(9: 4)</sup>. In addition to the external difficulties generated by the opinion or looks of others, impasses arising from the family itself occur, who often do not understand the specificities of autism. Thus:

[...] the family also experiences mental fragility, caused by the fear of the new, different, unexpected situation and prejudices of society. Preconceptions within the family are usually hidden, and unknown, but appear the instant they have contact with this family and social reality<sup>(9:11)</sup>.

As a result of these questions, many parents absorb the difficulties that their children might eventually encounter. In the discourse of one father, it was noticed how much the father places himself in the place of his son, sometimes preventing him from constructing his own story. In addressing this question, authors<sup>(18)</sup> evaluate that "[...] the family that has this kind of reaction with their autistic child, who experiences the child's problems as if it were their own and tries to resolve any conflict that they may face, but, the child has to have their own individuality, chosen by them, to express their feelings"<sup>(18:79)</sup>.

*Aldebaran is experiencing a time that is not his own and sometimes tries to live a life that does not belong to him. He needs to let his child live [...] upon the arrival of his son, and his diagnosis, Aldebaran fears that he will suffer the same things that he suffered. He fears that his son will suffer the same prejudices that he has gone through. What a huge weight he puts on his son. I expressed to Aldebaran how much weight he places on his son's life, things that may not even occur. It's a giant weight.*

The meetings with the research collaborators made it possible to reveal the meanings of the professional and client meetings and the parents of autistic children who were attended in a Psychological Service. Each parent / caregiver spontaneously sought care in the service; they kindly accepted to speak about their experiences in this research, sharing their dreams, difficulties and day to day life with their children.

The versions of meaning explained how much the researcher was affected by the encounters, considering the experiences of their parents' lives, their visions of the world, requests for help and sometimes the need to "just" be listened to. The study participants felt at ease and talked openly about themselves and about their experience in the psychological service. They saw an opportunity to talk about themselves, without reservations, with the purpose of being listened to.

### **Conclusion**

This phenomenologically inspired research, based on the Person-Centered Approach, allowed the experiences of parents and/or caregivers of autistic children to be revealed. It was evident

that, despite the differences and singularities presented by the stories and demands that led them to seek psychological counseling, there are common uniting characteristics: mourning due to the diagnosis of autism, difficulties with child care and social isolation.

Regarding this study, it is important to emphasize that there is no intention to exhaust and generalize the comprehension regarding the meaning of the experiences of caregivers of autistic children, but to confirm that the intention is to unite with other researches and to shed light and strengthen this theme, which is considered relevant.

Finally, the importance of psychological services for these parents/caregivers is highlighted, which, according to this research, are people who suffer great impacts due to their autistic children.

### Collaborations:

1. conception, design, analysis and interpretation of data: Diana da Silva Nobre and Airle Miranda de Souza;

2. writing of the article and relevant critical review of intellectual content: Diana da Silva Nobre and Airle Miranda de Souza;

3. final approval of the version to be published: Diana da Silva Nobre and Airle Miranda de Souza.

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