

## The meaning of being a mother or father of a child with autism

### O significado de ser mãe ou pai de um filho com autismo

### El significado de ser madre o padre de un hijo con autismo

Received: 23/01/2017

Approved: 13/07/2017

Published: 30/03/2018

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The autism is characterized by impairment in communication, social interaction and the presence of stereotyped and repetitive behavior, interests, and activities. The objective of this study was to analyze and describe the meaning of being a mother or a father of a child with autism. Four women and two men participated in this study. All of them have a child with autism. Data were collected through a semi-structured interview and interpreted following a thematic content analysis. Following this analyzes it was created three types of categories named: "Impact of the diagnosis of autism"; "Emotions, attitudes, and feelings awake" and "Transformative experiences." It was verified that both the mothers and the fathers presented a tendency of overprotection and uncertainties related to the future of the child. It was concluded that it is a challenge to be a mother or father of a child with autism because it requires a huge dedication to cope with the needs of the child.

**Descriptors:** Autistic disorder; Family; Mothers; Parents.

O autismo é caracterizado pelo comprometimento na comunicação, na interação social e pela presença de comportamento, interesses e atividades estereotipados e repetitivos. O objetivo desta pesquisa foi analisar e descrever o significado de ser mãe ou pai de um filho autista. Participaram deste estudo quatro mulheres e dois homens com filhos com diagnóstico de autismo. Os dados foram coletados por meio de entrevista semiestruturada e interpretados seguindo a análise de conteúdo do tipo temática. Na análise do conteúdo das entrevistas emergiram as seguintes categorias: "Impacto do diagnóstico do autismo"; "Emoções, atitudes e sentimentos despertados" e, "Vivências transformadoras". Verificou-se que mães e pais apresentaram tendência de superproteção e incertezas em relação ao futuro do filho. Conclui-se que é um desafio ser mãe ou pai de uma criança autista por exigir total dedicação em prol aos cuidados que o filho necessita.

**Descritores:** Transtorno autístico; Família; Mães; Pais.

El autismo es un trastorno que compromete la comunicación y la interacción social, además de generar comportamientos, intereses y actividades estereotipadas y repetitivas. Esta pesquisa objetiva analizar y describir el significado de ser madre o padre de un hijo autista. Participaron del estudio cuatro mujeres y dos hombres cuyos hijos fueron diagnosticados como autistas. Se colectó a los datos por medio de una entrevista semiestructurada y se les interpretó con un análisis temático de contenido. En el análisis del contenido de las entrevistas, emergieron las categorías: "Impacto del diagnóstico de autismo"; "Emociones, actitudes y sentimientos despiertos" y "Vivencias transformadoras". Se verificó que las madres y padres tienden a proteger demasiado sus hijos y tener incertezas con respecto a su futuro. Se concluye que ser madre o padre de un hijo autista es un desafío, pues los cuidados de que el niño necesita exigen de sus padres dedicación absoluta.

**Descritores:** Trastorno autístico; Familia; Madres; Padre.

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## INTRODUCTION

The family plays a relevant role in the survival of the child. It is fundamental to his global development and it is considered the basis for the learning of social values<sup>1-3</sup>.

Relationships established among family members are interdependent and exert influence on one another, and any change that occurs in this context will exert influence on each individual member or on the whole system<sup>4</sup>.

For any family group, the birth of a child is a major event in their lives and requires some changes and restructuring of roles and functions, especially of the parents, to receive and include the new member in this group<sup>3,5</sup>.

When the child has some type of disability, it can lead to family disruption, arousing an initial feeling of fear and mourning for the loss of the perfect child<sup>6</sup>. Parents may become frustrated and feel responsible for the condition presented by their child. Mothers are more likely to develop depression because they are culturally responsible for the care and education of their children with disabilities compared to mothers of children with typical development<sup>1,4</sup>.

Commonly, the women are who give up paid work and careers to dedicate fully to the care of their children<sup>4</sup>. Thus, the birth of a child already causes a change in family organization and dynamics, which can be challenging for parents when the child presents organic, genetic or acquired changes that cause the child to have difficulties interacting with the environment<sup>1,7</sup>.

Autism is among these possible developmental changes, which is characterized by behavioral abnormalities in social integration, impairments in verbal, non-verbal communication, creative activity, and interests in repetitive and stereotyped activities<sup>5,8</sup>.

Stereotypies are involuntary, repetitive, rhythmic, coordinated body movements with no specific functional purpose. They may be associated with periods of stress, excitement, boredom or tiredness,

and they can last from seconds to minutes, with a varied occurrence throughout the day<sup>9</sup>.

Autism begins before three years old, with a prevalence of 1 in every 68 births, predominantly in males, and may be due to pre, peri and postnatal conditions<sup>10,11</sup>.

The characteristics presented by a child with autism can affect his relationship with his whole family<sup>12</sup>. Also, due to his difficulty in acquiring autonomy and his dependence on family members, the child may contribute to the disruption of the activities of the family group, and often some families begin to live only for the child<sup>3,12</sup>. Consequently, the family is in a situation where it needs to adapt constantly to be able to be dedicated to the child<sup>7,12</sup>.

Thus, the guiding question of this research was: What is the meaning of being the mother or father of an autistic child? The term meaning was used to understand the daily experiences of parents of children diagnosed with autism.

The purpose of this research was to analyze and describe the meaning of being the mother or father of an autistic child.

## METHODS

This study was characterized as a descriptive and exploratory research with a qualitative approach. This type of approach was chosen because it allows exploring aspects of a given situation and describing the characteristics of a given population or phenomenon<sup>13</sup>.

This methodological design allows a man to be able to reflect on himself and interpret the phenomenon he observes. There are no preconceived hypotheses since they are constituted after observation of the phenomenon studied<sup>14</sup>.

This study was carried out in the Central Pediatric Outpatient Clinic of the Federal University of the Triângulo Mineiro (UFTM) and the Center for Guidance and Research in Special Education (CEOPEE), located in the city of Uberaba-MG, from April to September 2013.

Four women and two men with children in the age group of three years old and seven months to thirteen years old, with a

diagnosis of autism participated in the study. The parents' age range was between 25 and 49 years old and their level of education is at the secondary or higher level.

The following inclusion criteria were considered: parents of children with autism, who accepted to participate in the study, agreed to the criteria and signed the Free and Informed Consent Term (TCLE). These parents were recruited by invitation of the researchers and for being linked to the services in which UFTM provides assistance, through curricular internships and extension projects.

For data collection, semi-structured interviews were conducted, with a script prepared by the researchers in the Microsoft Word version 2010 program, individually with parents and mothers in the room for individual care in the pediatric outpatient clinic and the Center for Orientation and Research in Education Special (CEOPEE). It lasted approximately one hour and at times scheduled by the participants at their best convenience.

The interviews were recorded with the permission of the parents, transcribed in full and checked twice by two researchers, to ensure the reliability of the transcript.

The data were analyzed using the thematic type content analysis technique, following the pre-analysis phases; exploitation of the material; treatment and interpretation of the results<sup>14</sup>.

In the pre-analysis, the contents of the interviews were checked for the comprehension of the aspects raised in the questions of the semi-structured script: How was your life before being the mother/father of an autistic child? How was the pregnancy? How did you know your son was autistic? How is your life today? How is your relationship with the child? For you, does your child have any autism-related difficulties? What strategies do you use to deal with your child?

In the material exploration stage, a table was created containing all the answers to the questions described above, aiming to reach the core of understanding of their reports.

In the treatment stage of the obtained results and their interpretations, a second table with the answers of the participants was created and the interpretation of the similarities of the present answers was held. Thus, it was possible to aggregate the data by specifying sense cores.

In the presentation of the results, the terms "M" (Mother) and "F" (Father) were sequenced by Arabic numerals to identify the relatives of children with autism.

Since it is an investigation involving human beings, the research project was submitted to the Research Ethics Committee of the UFTM, being approved under the Opinion No. 2,497 of 2013, as recommended by Resolution 466/12 of the National Health Council (CNS)<sup>15</sup>.

In order to comply with the ethical principles of the aforementioned resolution, the participants involved in the research were informed and clarified about the objectives of the aforementioned resolution and then signed the agreement in writing, signing the Free and Informed Consent Form (TCLE) in two copies, staying with one of them and leaving the other one with the responsible researcher.

## RESULTS

After analyzing the data through maternal and paternal responses, related to the semi-structured interview script, three cores of meanings were created and organized that expressed important meanings in being a mother or father of a child with autism.

These cores of meanings were named: a) Impacts of the diagnosis of autism in motherhood/fatherhood; b) Emotions, attitudes and feelings awakened in motherhood/fatherhood; and c) Transformative experiences in motherhood/fatherhood.

The first core of meaning refers to the impact of the diagnosis of autism on motherhood/fatherhood and it was evidenced in the reports below of these fathers and mothers that at the beginning the news about this health condition of their child caused them frustration, sadness, heartache, and denial. The greatest similarity among the

participants was the need for guidance on what autism meant and what to do about it:

*I accepted, to be honest, but at the same time we were afraid because many people sometimes criticized that he had a problem... I discovered that my son had autism with three to four years old (M1).*

*When I traveled, I noticed that she had something different and she did not sleep, she radically changed the facial expression, the behavior, it happened at once, she became another person and she was a year and a half (...) I cried, I cried, I wanted to die (M2).*

*I never thought about having a problem child, we were afraid... when he was born he had no deformity whatsoever, he was born healthy, he was great, everything was normal... a year later he started with those repetitive and stereotyped movements (F2).*

*We have a bit of a schism later on with his relationship with other children... if other children will not flatter him, he will "discard" him, but it's something I do not think about, but I'm afraid of the future (F1).*

*My fear is that I die and he is left in the hands of those who have no patience, so I always ask God to give me health. I want to see him grow (...) he needs me so close (M4).*

Through the reports of the mothers and fathers, it was observed that the special characteristics of autism occurred in their children before three years old.

When faced with the limitations of their children, feelings of anxiety, disappointment, worry, guilt, and fear arose in their parents. Faced with these feelings there were uncertainties about the child's development. Thus, the timing of diagnosis brought more difficulties of acceptance for some parents than for others.

The second core of meaning refers to the emotions, attitudes, and feelings experienced by the mothers and fathers of children with autism. It may be noticed that mothers sought to establish an affectionate relationship with their child with autism. They reported that they loved their children unconditionally and regardless of diagnosis.

The parents showed a tendency to overprotect the child with autism, always wishing to have them around:

*My relationship with my son is good. I have a lot of love, because he is special, there are people who do not accept that I treat him as special, but for me he is. Especially in the sense that I pay more attention and I have to dedicate myself more to him, that is why I say that he is special for me, but I treat him like any other child. If I have to be hurt, if I need to correct I correct (M3).*

*We get a little more jealous of him. I'm kind of worried about dropping him even with the grandparents, I*

*wonder maybe they'll drop him and get hurt because he stumbles a lot (F1).*

*One day I even told my wife to stop talking to the others that he (son) likes to watch the fan turning because this is characteristic of troublesome people (F2).*

For the interviewed mothers, it was a challenge to be the mother of a child with autism because of the need for care that this child needed, there was no time left to dedicate themselves to the other children who did not have autism and to their husbands:

*I am very tired, worried (...) and men sometimes do not understand (M3).*

*My affectionate relationship with my ex-husband has changed because we separated, but he helped in part because he (son) does not see a fight and already sees something calmer (M1).*

*Tive vários problemas familiares, eu com meu marido e eu com meus filhos, principalmente com meus filhos, os diálogos não conseguiam se entender (M2).*

*I had several family problems, my husband and I with my children, especially with my children, the dialogues could not understand (M2).*

Through these reports mentioned above, it was noticed that the mothers of these children with autism were intensely dedicated to the care of the child. So they could not be very present in the lives of their other relatives.

The third core of meaning referred to the transformative experiences in motherhood/fatherhood from autism. It was observed that before the diagnosis of autism, life was reported as quiet for most mothers. Some of them worked and some did not. However, all were unable to work after the diagnosis:

*I did not work, but I helped my mother at home. I studied and did an art education course and sold blouses, but I was quieter and had no worries. The job is hard for me because if I go to work, my head always stays here, I know I have to work, I know my obligation, but I worry about him all the time (M1)*

*My house was in a quiet moment. She was in the routine of a normal housewife, taking her children to school and searching. I always had a person on the right guard who helped me, who made food, who took care of the house (maid) (...) I worked part-time, more after the diagnosis of autism, that's it, now I just stay at home (M4).*

Through these reports, these mothers reported that before they had an autistic child, they were not as worried and some dedicated to taking care of their other children.

After learning that their child was autistic, there were significant changes in their lives, as they had to quit their jobs, which

had a financial impact on the family budget and also an emotional impact due to the loss of financial independence. Thus, the mothers had difficulties in pursuing their professional career, dedicating all their time and energy to take care of the child.

Some mothers reported that they were selfish, impatient, and intolerant.

*Before I had J. I was completely different, I was selfish, I felt that things had to be better for me, I went into a world, so that was not all in the way I thought it was, it was not. J. made me be a quieter person, I learned to be patient because not everything happens at the time we want. We happen to see people with different eyes, I did not have contact with disabled people and now everything has changed (M3).*

*I think I've changed a lot as a person in every way. I really am a more tolerant person (M2).*

One of the mothers mentioned that when she had her first child, she did not know how to handle the role of mother and acted aggressively when her son did not comply with her orders, but with the arrival of the autistic child, she was able to recover those experiences and transform them into beneficial attitudes to care and offer every affection for both autistic child and the other children:

*I have a clear conscience, because in G. (autistic son) I do not beat, but in V. I beat a lot, out of ignorance and even nervous, because he did not want to eat, he was very "small" and had anemia, there I said, V. you have to eat and if he did not eat I would pat him, I would do it even because I was laying in creation and it was the first time I was a mother. To this day, my conscience hurts because I hit V. (...) which I did not enjoy with the V. I take advantage of G. because with V. I had to work, leave him in a daycare, so it was very difficult with V. and G. is not so much (M4).*

From these reports, it was noticed that the mothers experienced difficulties arising from caring for the child with autism, but this process led to the initiation of positive transformations in the way they "saw" the world related to their respective daily and family niche.

This fact is evidenced in the examples of the reports of the M3 mother who said that she had no contact with children with disabilities and that she considered herself a selfish person because she felt that everything for her should be "of the good and the best" and after this experience of having a child with autism she became a less selfish person.

Mother M4 reported that when her son did not want to eat, she "beat him" because she thought that was the only way to feed him because he already had anemia and she was afraid he would get sick. In relation to the autistic child, she will not use this same "resource" as it was clearly demonstrated in her report.

It should be noted that parents reported that it was a positive transformative experience in having a child with autism because they assumed a greater commitment to fulfill paternity, changing their visions towards the family, as observed in the stories: *I think it's good to have an autistic child because we start to see the world differently. When I was younger I did not play with children, now when I see a child, I already talk and play (F1).*

*I am having this experience now... my two children I had in previous relationships I did not raise, but this one I want to raise him. So my coexistence with him is like a real father with the child present every day (F2).*

## DISCUSSION

Global developmental disorders involve conditions that bring about social changes<sup>16</sup> with limitations in other individuals, the presence of language and communication deficits, learning and cognition difficulties, and the presence of a restricted repertoire of activities and interests<sup>10,17</sup>.

All these characteristics have important developmental consequences, both for the diagnosed child and for their parents and caregivers<sup>18</sup>.

Somehow, such characteristics will impact the daily life of parents, as it will require routine adjustments, activities of daily living and social participation. In this study, the term routine referred to patterns of behaviors and attitudes that are observable, regular, repetitive and that provide structure for daily living. The activities of daily living were defined as those oriented to the care of the person towards his own body and social participation as organized patterns of behavior that are characteristic and expected of a person or a given position within the system<sup>19</sup>.

In the course of the experiential process of caring for the autistic child, parents are losing the characteristics of their daily life, starting to assume the daily routine of the

child<sup>10</sup>. Autism often leads members of a particular family context to experience disruptions, interruptions, and adjustments in their social activities<sup>4,5,20</sup>.

In the study presented here, the mothers reported that because of autistic child care, there was no time left to be dedicated to other children who did not have autism and to their husbands. Corroborating with studies that show that mothers for their full-time dedication to the care their autistic child needs, they commonly undergo changes in their emotional relationships as a result, and often sacrifice as a woman, wife, and their professional life<sup>16,21</sup>.

Also, the brother of an autistic child often faces parental absence due to the great attention paid to his brother, who needs full-time attention and visits to health professionals routinely<sup>22</sup>.

It is important to emphasize the importance of the diagnosis and its impact on the mothers and fathers of children with signs of autism<sup>23</sup>. According to the reports of the mothers and parents interviewed, the special characteristics of autism occurred in their children before three years old. This is in agreement with studies that show that autism, because it is a condition defined by changes present at early ages, most often occurs before three years old<sup>24,25</sup>.

The child with autism presents a unique triad, characterized by the difficulty and qualitative impairments of verbal and non-verbal communication, social interactivity and the restriction of their cycle of activities and interests, and stereotyped movements may still be part of the symptomatology<sup>26</sup>.

It can be seen that these clinical signs of autism can arise and be verified in the first years of life<sup>26</sup>. When performed early, diagnosis can have positive consequences for the developmental prognosis and, especially, the cognitive of the child and for parents to feel empowered in the search for treatments for their children<sup>25</sup>.

Concerning independence, approximately two-thirds of autistic children are commonly unable to live independently and only one-third can attain some degree of

personal independence and self-sufficiency as adults<sup>27</sup>. Thus, it is natural for parents to be concerned about whether their children will be independent and whether they will be able to relate to others, especially in the event of their absence.

It is also worth noting that early treatments may impact the level of (in)dependence of these children, empowering them to be more independent, productive and effective adults. However, there is a need for public policies that can provide early and continuous intervention that address both issues related to the development and inclusion of these children as therapeutic approaches for their parents and family.

The historical, political and social context varies from one country to another, depending on the degree of familiarity with the treatment theme and evolution, as well as the capacity of the health and educational services to cover these families. All of these issues can impact families who experience autism in their daily lives.

It is known that the family is a complex network composed of different members that have their social functions defined culturally, and that establish themselves by forming emotional interrelations, where individuals have with other people some kind of social support and support and through from which they receive emotional support<sup>1</sup>.

Due to the specific characteristics of autistic children's behaviors, besides the severity of the disorder, potential stresses may be formed for all members of the family<sup>5,6</sup>.

Corroborating with studies that show that the discovery of a pathology, deficiency or alteration in a child brings repercussions on the life of parents and the family as a whole and facing this new and unexpected reality can cause frustrations and suffering in the family with a child with autism<sup>16,24,28</sup>.

These facts justify the reasons for the conflicts that several mothers of the research reported in their experience with the child with autism. It can be verified that both mothers and fathers experienced various emotions and experienced sentimental ambiguities.

In the interviews, there were moments of happiness and personal growth, emotional support and a network of support, but also moments of deep anguish and sadness, insecurity, and fear of the future. The commitment of motherhood and the autistic child's dependence on the mother causes them to seek the strength to continue adapting and always changing in search of improvements that provide well-being for the child and the family.

At the same time, an overprotective attitude is created towards the demands that the child with autism needs in their daily lives. Both mothers and fathers bring fear and excessive apprehension for the future of the child as a consequence of this attitude of protection when she is no longer present.

Parents tend to be judged as the only ones who know how to take care of their child, and distance other potential caregivers<sup>21</sup>; and attempt to resolve any conflict that the child might face<sup>29</sup>. This ambiguity creates conflicts and arouses emotional instability for some parents.

It can be verified that there was an approximation of family members who became sensitized with the family situation and became people closer to these parents. This approach was of paramount importance as it provided them with the emotional support needed to deal with the difficulties of the child care process.

When the family is able to adapt well to a new fact that occurs in their lives, they have a greater capacity to respond effectively to a stressful situation and to make decisions to solve it<sup>10</sup>. However, mothers and fathers cannot predict what will happen to the child with autism in the future. When a child presents no developmental impairment, it may be facilitated for parents to idealize the future of their children, but if a child with autism is born in the family core, the future becomes a question mark for parents and caregivers<sup>4</sup>.

Isso pode ser visto nesta pesquisa e mencionado diversas vezes pelos pais. Consequentemente, o futuro das crianças com autismo, pode causar nos cuidadores angústia sobre as incertezas do que ocorrerá com o

filho, quando não estiverem presentes em suas vidas.

This can be seen in this research and mentioned several times by parents. Consequently, the future of children with autism can cause caregivers anguish over the uncertainties of what will happen to the child when they are not present in their lives.

Despite all the difficulties parents face in their daily care of their child with autism, this coexistence can cause significant changes in the way they see life<sup>17</sup>. It enabled them, according to them, personal growth, enrichment of family relationships and maturity of maternal and paternal roles.

Both mothers and fathers mentioned having undergone major transformations that changed their "life optics", and all this because of the presence of a child with autism in the family niche. This corroborates with a study that shows that many mothers who can overcome the fact of having a child with a disability present a new meaning about this situation<sup>21</sup>.

The parents interviewed reported that it was a positive experience to have a child with autism, and to make a greater commitment to fulfill paternity. In one study, it was stated that the father's view that he is one who performs only the role of provider of family and children has been replaced by the perception that he is a member that can play significant roles such as a caregiver, protector, and companion<sup>30</sup>.

## CONCLUSION

This study demonstrated that being a parent of a child with autism was a major challenge due to the characteristics of this health condition that required parents' full dedication to child care.

Emotional instabilities related to the diagnosis and the caring process were experienced, as well as how emotions and attitudes were generated regarding the needs of the child and adjustments in family life and routine.

Despite all the difficulties faced, these parents experienced transformative experiences in their roles of mother and father. This experience promoted personal

changes in their lives, as they became more tolerant and patient people, not letting children lack love and care in the home.

This study shows the need to create networks of social support, health, and education appropriate to the care of families with children with autism and to promote the integrality of care.

One of the limitations of this study is the number of participants, which prevents generalizations for other families of children with autism. Thus, it is suggested that future research with the same theme be carried out with other parents and caregivers.

Despite the small number of participants, the results of this study may be to rethink the practice and management of health.

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#### CONTRIBUTIONS

**José Henrique da Silva Cunha** participated in the design, design, analysis, and interpretation of data and writing. **Diane Coelho Pereira** worked in the analysis, interpretation of data and writing. **Lucieny Almohalha** contributed to the design, project, analysis, and interpretation of data, writing, and critical review.

#### How to cite this article (Vancouver)

Cunha JHS, Pereira DC, Almohalha L. The meaning of being a mother or father of a child with autism. REFACS [Internet]. 2018 REFACS [Internet]. 2018 [cited in: *insert day, month and year of access*]; 6 (X): XXX-XXX. Available from: *enter access link*. DOI: *insert DOI link*.

#### How to cite this article (ABNT)

CUNHA, J. H. S.; PEREIRA, D. C.; ALMOHALHA, L. The meaning of being a mother or father of a child with autism. REFACS, Uberaba, v. 6, n. X, p. XX-XX, 2018. Available from: < *enter access link* >. Accessed in: *insert day, month and year of access*. DOI: *insert DOI link*.

#### How to cite this article (APA)

Cunha, J. H. S., Pereira, D. C. & Almohalha, L. The meaning of being a mother or father of a child with autism. REFACS, 6 (X), XX-XX. Retrieved in: *insert day, month and year of access* from *enter access link*. DOI: *insert DOI link*.