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# BECOMING THE MOTHER OF A CHILD WITH CEREBRAL PALSY: FEELINGS EXPERIENCED[1]

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**ABSTRACT. Objective:** to understand the woman's experience of becoming a mother of a child with special needs from cerebral palsy. **Methodology:** this was a qualitative, phenomenological hermeneutic study carried out in a municipality in the north of the State of Rio Grande do Sul, Brazil, with ten mothers who were caring for children/adolescent with cerebral palsy between April and June 2015. Phenomenological interviews were used to collect information. The interpretation included the hermeneutic approach. **Results:** the mother upon receiving the diagnosis of cerebral palsy goes through a reorganization of her habitual way of being-in-the-world to adapt herself to the new existential situation. From that moment on, she started to live according to the child's care. **Conclusions:** This study provides the possibility of reflection for health professionals in order to understand the whole process experienced by the mother, helping her in this new existential situation, understanding her in the phases that make up the process of adaptation to the condition of being the mother of a child with cerebral palsy.

**Keywords**: Mother; cerebral palsy; care.

# TORNAR-SE MÃE DE UMA CRIANÇA COM PARALISIA CEREBRAL: SENTIMENTOS VIVENCIADOS

**RESUMO. Objetivo:** compreender a vivência da mulher ao tornar-se mãe de uma criança com necessidades especiais decorrentes da paralisia cerebral. **Metodologia**: estudo qualitativo, fenomenológico/hermenêutico, realizado em um município ao norte do Rio Grande do Sul/Brasil, com dez mães/cuidadoras de crianças/adolescentes com paralisia cerebral, entre abril a junho/2015. Para a coleta de informações utilizou-se a entrevista fenomenológica. A interpretação compreendeu abordagem hermenêutica. **Resultados**: a mãe ao receber o diagnóstico de paralisia cerebral ocorre uma reorganização do seu modo de ser-no-mundo para se adaptar à nova situação existencial. E, a partir desse momento, inicia um viver em função do cuidado do filho. **Conclusões**: o estudo traz a possibilidade de reflexão para os profissionais de saúde a fim de compreender todo o processo vivenciado pela mãe, auxiliando-a nesta nova situação existencial, compreendendo-a nas fases que compõem o processo de adaptação à condição de mãe de uma criança com paralisia cerebral.

**Palavras-chave:** Mãe; paralisia cerebral; cuidado.

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# CONVIÉRTETE EN MADRE DE UN NIÑO CON PALSY CEREBRAL: SENTIMIENTOS EXPERIMENTADOS

**RESUMEN. Objetivo:** comprender la vivencia de la mujer al convertirse en madre de un niño con necesidades especiales derivadas de la parálisis cerebral. **Metodología**: estudio cualitativo, fenomenológico hermenéutico, realizado en un municipio al norte del estado Rio Grande do Sul, Brasil, con diez madres cuidadoras de niños adolescentes con parálisis cerebral, entre los meses de abril a junio del 2015. Para la recolección de informaciones se utilizó la entrevista fenomenológica. La interpretación comprendió el enfoque hermenéutico. **Resultados**: la madre al recibir el diagnóstico de parálisis cerebral pasa por una reorganización de su habitual modo de ser en el mundo para adaptarse a la nueva situación existencial. A partir de ese momento, pasa a vivir en función del cuidado del hijo. **Conclusiones**: este estudio da la posibilidad de reflexión para profesionales de la salud a fin de comprender todo el proceso vivido por la madre, ayudándola en esta nueva situación existencial, comprendida en cada una de las fases que componen el proceso de adaptación a la vida en condición de madre de un niño con parálisis cerebral.

**Palabras clave:** Madre; parálisis cerebral; cuidado.

## Introduction

The arrival of a new member to the family is an event that produces many changes in the family nucleus, which are linked to emotional, physical, behavioral, social and economic aspects. In this sense, the family starts to reorganize as ‘being-in-the-world’ to welcome the new being.

The impact of disclosing the diagnosis of cerebral palsy to parents creates an initial shock. It becomes a difficult, sad, complicated moment, causing a lot of insecurity and fear, especially the mother, the main caregiver. Uncertainty and insecurity are present at this moment, and the meaning of life for mothers is materialized in the process of caring for the child (Smeha et al., 2017).

Cerebral palsy or chronic non-progressive encephalopathy in childhood is one of the most complex deficiencies. Resulting from a static lesion in the brain during the developmental period, it can occur in the pre-, peri- or post-natal period. The main etiological factors are related to maternal circulatory changes, infections, eclampsia and placental abruption, prematurity and low weight, severe jaundice, asphyxia, instrumental delivery, epileptic syndromes, traumatic brain injuries, among others. Clinical manifestations in children correspond to sensorimotor disorders with changes in muscle tone, posture and voluntary movements (Mancini et al., 2002).

In this sense, due to the severity of the disability, the disclosure of the diagnosis is a complex moment, in which the parents are not prepared to receive this news and health professionals, in turn, have difficulties in dealing with the disclosure, often using a language that escapes the understanding of these parents, expressing insecurity and little sensitivity in relation to the suffering that causes such news (Silva & Ramos, 2014).

From this perspective, the family, faced with the diagnosis of Cerebral Palsy, tends to disorganize at first, changing the usual family routine and dynamics; needing to rethink and seek available support to reorganize as *being-in-the-world* and regain balance to face this existential facticity (Gondim & Carvalho, 2012).

It is worth considering that the family, especially the mother, when receiving the diagnosis of her child's cerebral palsy, but, mainly, when understanding what it means to have cerebral palsy, she experiences a process of bereavement, for the death of the imagined child. In this context, one can make an approximation between the process experienced by the mother facing the birth of a child with special needs and the process of bereavement for the dreamed and idealized child (Oliveira & Matsukura, 2013).

In this perspective, the mother, when having a child with special needs, begins to face the loss of the dreamed child, experiences the anguish of this facticity, the confrontation of social and family prejudice and, sometimes, of self-prejudice, a blame in relation to her woman ability of generating a baby within the standard of normality, established by a normative and oppressive society towards the different ones. In addition to the self-demanding of the mother, there is also pressure from health professionals, society, the family, towards a full dedication of the mother to the child with special needs (Ribeiro, Vandenberghe, Prudente, Vila, & Porto, 2016).

Taking into account these premises, from the moment of the news of the diagnosis of cerebral palsy, a new reality must be assimilated and a series of emotional, structural and financial adaptations are necessary for the family, especially the mother, the main caregiver. Fernández-Alcántara et al. (2013) point out that, in particular, mothers, although they do not experience the oppression of the body, experience the universe of disability in another way, having to give up his personal and social life to dedicate to the care of the child, acquiring a new 'way-of-being-in-the-world' in the face of this existential facticity.

This existential facticity leads to anguish, which goes beyond the feeling towards the unknown, it is configured as an existential situation, in which the mother of the child with cerebral palsy needs to overcome this facticity, which allows the human being to give new meanings to its existence, rediscovering a new way of living and seeing life. For Heidegger, anguish is something profound, it allows reflections, because man sees himself in nothing or nowhere, which is not only anguish with, but anguish for, which creates the possibility of 'can-be-in-the-world' and project itself essentially towards possibilities (Heidegger, 2012).

The hermeneutic interpretation of Ricoeur (1978) allows for reflections, requires an ontological attitude. In this context, the world announced and recreated asks to be understood. It is through words that one can rescue the gesture, the said, the unsaid, the lived, the not lived, in the temporal sense of presence.

Research shows that mothers report very significant changes in their lives, in every way, and the family restructuring process depends, in large part, on how the parents understand and accept the diagnosis (Nimbalkar, Raithatha, Shah, & Panchal, 2014). Such changes are reflected in the world of work, which many are forced to leave behind, with individual desires and dreams, due to the concentration of all energies and efforts towards a single objective, which is to take care of the child with special needs.

Thus, the demands for care are intense and constitute challenges for the family caregiver, particularly for the mother. For family caregivers, children create greater demands for care in terms of constancy, vigilance and intensity (Oliveira & Poletto, 2015). In this sense, the objective of this study was to understand the woman's experience of becoming a mother of a child with special needs resulting from cerebral palsy.

## Methodological route

This was a qualitative study anchored in the conception of the hermeneutic phenomenology of the philosophers Heidegger (2013) and Ricoeur (1978). This study is represented by ten caregiving mothers of children/adolescents with cerebral palsy, aged 5-11 years and adolescents aged 12-18 years, of an Association of Parents and Friends of Handicapped Children (APAE) of a municipality located in the north of the State of Rio Grande do Sul, Brazil. The age of 5 years was defined, which includes the school age of the child, so the mother may have greater experiences in relation to the experience with the child.

The information originated from phenomenological interviews, from April to June 2015, guided by the questions: what was it like to become the mother of a child with special needs? What is it like to take care of a child with special needs?

The inclusion criteria were considered: being the mother and caregiver of the child/adolescent with special needs resulting from Cerebral Palsy; the child/adolescent is between 5 and 18 years old; attend the study site; not being on a trip or away from the institution during the period of data collection and the mothers are 18 years of age or older. And, exclusion criterion: presenting difficulty in verbal communication.

In order to maintain anonymity, the information will be presented by the initials M (Mother) and identified by a number from 1 to 10, consecutive according to the order of the interviews. The material resulting from the interviews was organized and interpreted based on the proposal for hermeneutical interpretation of Paul Ricoeur (1978).

In compliance with the ethical precepts provided for by Resolução nº 466 (2012), the study was approved by the Research Ethics Committee of the College of Medicine (FAMED) of the Federal University of Pelotas (UFPel), under the opinion 1.001.573, as of26 de march de 2015.

## Unveiling meanings

The mothers participating in the study are aged between 22 and 50 years old, and the number of children varied from one to three. As for the educational level, from basic education to complete high school. The socioeconomic status varied from one to two minimum wages. The children are four to 18 years incomplete, all diagnosed with cerebral palsy, and of these, three have difficulty walking and use their hands for daily activities, the rest are totally dependent.

Following is the theme apprehended when unveiling the woman's experience of becoming the mother of a child with cerebral palsy:

### At first, shocking: becoming the mother of a child with cerebral palsy

Many women dream of becoming a mother since they were little, however, they do not imagine that their child can be diagnosed with cerebral palsy and develop special needs. The family, especially the mother, is distressed, going through a state of shock, until gradually (re)organizing her way of 'being-in-the-world' to adapt to the new situation. During the dialogue with the participants, it was noticed that everyone wanted to become a mother, as can be seen in the following reports: “It was planned, I wanted to get pregnant. During the nine months of pregnancy I prayed and asked God to give me a baby, whether a girl or a boy, who would come healthy to do God's work” (M4).

> I always dreamed of having a child, even before I got married [...] I thought of the name, if a boy or girl, in short, we always dreamed of having a child. [...] even when I got pregnant we had a motorbike, we didn't even have a car, then my husband was already planned to have to buy a car to walk with the baby, that emotion you know we always dreamed of having, imagined the baby that we always dreamed of having (M1).

The woman, usually, when she dreams/plans to have a child, starts to awaken this feeling from childhood, in games. Therefore, it is considered that the child's psychological birth occurs before the chronological birth (Maldonado & Dickstein, 2010; Milbrath, Motta, Resta, & Freitag, 2016). The woman is sculpting in her 'fantasies', conscious or unconscious, her projections in relation to this new being that is being generated (Milbrath, 2013).

Throughout its existence, the woman is programming the future she intends to experience, this is because every human being is a temporal being, that is, *Dasein* is not restricted in its consciousness to the present moment, but projects itself into the future and goes backwards to the past (Milbrath, 2013; Heidegger, 2013). Furthermore, in the Heideggerian perspective, the being is built while and because it exists (Heidegger, 2017).

In this sense, the woman as a temporal being, projects in her imaginary the future she intends to experience in the course of her existence. During pregnancy, she plans the future, in this case, the child she wants to have, creates in her imagination the physical and psychological characteristics of this new being. In this future project, she does not consider the birth of a child with special needs (Milbrath, Motta, Gabatz, & Freitag, 2017).

Thus, when the child suffers a complication and starts to live in the world with the special needs resulting from cerebral palsy, the mother experiences a totally different present from the future plans that she had prepared in the past (Almeida, Gonçalves, & Maciel, 2015), making her need to (re)organize her way of 'being-in-the-world'.

The research participants expressed their desire in relation to motherhood, reported that they dreamed of the child, imagined what the name, the sex; projected the future they intended to experience. However, these mothers did not imagine that the child could come in a condition that developed special needs, as can be seen in the statements that follow: "It was a shock, of course, no mother is waiting! You are pregnant, expecting a child, will you expect the child to have a problem? Full of dreams, full of plans for him, suddenly that dream was gone. Bah! It was very difficult" (M2). "I imagined a healthy child, even more because it was a girl, I only had a boy" (M10).

The testimonies express the disruption of the projects in relation to the child, as well as the feeling of shock/disappointment generated by the birth of a child different from the maternal perspectives and different from the normal standards imposed by society.

The family experiences a moment of incomprehension in relation to the fact that a baby was born different from the idealized/dreamed, thus modifying the future that they had planned, it becomes a traumatic and destructive moment (Polidori, Capalonga, Franceschi, Frantz, Medeiros, Pereira, & Wazlawick, 2014). In this sense, the child who lives with cerebral palsy starts his/her existential trajectory in a shaken way (Milbrath, 2013), in contrast to what his/her mother dreamed of.

The mother experiences the anguish of her situation as a caregiver for a child with cerebral palsy, there is an awakening to her own existence, coupled with a reality that is alien to her dreams. This awakening causes profound changes in her view of the world. The caregiving mother extracts from her anguish the resignification of her existence, building a new path marked by finitude and austerity (Pereira, Matsue, Vieira, & Pereira, 2014).

In addition to experiencing a gift different from what they had designed, mothers still experience the ‘weight’ of normal standards, imposed by a socially defined paradigm, as if every human being should be equal (Milbrath et al., 2016): “I didn’t even know how to take care of a normal child, imagine a baby like that” (M1). “When I was a baby, I noticed that she was not normal” (M7). “I thought she was healthy and very normal” (M10).

From this perspective, the mother, in addition to experiencing the shock of having a child different from what she had dreamed of, experiences the feeling of helplessness and uncertainty (Polidori et al., 2014) for not being able to generate a child according to these socially imposed standards. In this context, generating a child that corresponds to these normatized standards causes women to feel a sense of competence, of capacity to perform her role as a mother, while the birth of a child with special needs breaks this feeling (Milbrath, 2013).

We live in a society that constantly seeks human ‘perfection’, whether in the social or genetic field (Milbrath et al., 2016). In this sense, the mother as ‘being-in-the-world’ suffers influences from this world, that is, from society and, consequently, from the current normal standards.

Going against these socially imposed standards is a difficult task. These mothers end up fighting a battle for self-acceptance of the child with special needs and another for the normative and oppressive society in which we live.

The families of children with special needs need to learn to live with differences, as they understand that each human being exists in the world in a unique way, with the potentials and limitations that give him/her his/her condition as a human being.

Upon receiving the diagnosis that the child has cerebral palsy, not only the mother, but the whole family suffers from the process of loss and bevereament of the idealized child and the need for insertion in a world of unknown needs. Tomorrow becomes uncertain, as the child’s condition was not part of family expectations: “At first it was a shock, we found out she had cerebral palsy, she was about seven months old, she started to convulse” (M6). “In the beginning it was difficult [...] He was born well, the heel stick test was ok, I just think it was a birth after the due date” (M7).

> A surprise! In the beginning, it was a shock. What will it be now? What are we going to do? I didn’t even know how to take care of a normal child, imagine this way [...] very difficult, everything new we just wanted to cry, we left the medical offices desperate with each exam and with what we heard (M1).

It can be seen that the impact of the diagnosis of cerebral palsy causes anguish, despair, shock and fear of the unknown. Participants in other studies also mentioned the initial impact as one of the most difficult moments in the process of adapting to the child’s existential condition (Ribeiro et al., 2016).

Experiencing a gift different from the projected one leads mothers to face, in addition to a new situation, something hitherto unknown. The human being, in general, fears what he/she does not know. Studies show that women feel alone to care for their dependent child, while the father who could help her is working outside (Ribeiro et al., 2016; Milbrath, 2013). Mothers are frightened by the unknown and the fragility of the child with cerebral palsy. In this sense, there is a resignation of the fact, the death of the dreamed/planned baby and the beginning of adaptation to this new situation according to the child’s condition.

What is feared is always an entity that meets the ‘being-in-the-world’ and brings with it the character of a threat. Fear manifests itself as pre-occupation with existing. For

Heidegger (2013, p. 138), “[…] fear is characterized as an improper disposition [...] fear is to fear what threatens. It is about what is detrimentally close to the can-be of presence”.

The anguish generated by the adaptation process to the new being, makes the mother acquire adaptation strategies. For Heidegger, anguish reveals the being for the can be more proper, that is, it allows the freedom of choice, to choose oneself and to resignify its existence, assigning a new value and acquiring a new way of being and ‘being-in-the-world’ taking care of the child and taking responsibility for this being (Heidegger, 2012).

The process of assigning a new value to the way of ‘being-in-the-world’ occurs slowly and gradually, passing through all members of the family, depending on the family structure, functioning, cohesion as a group. In this sense, the importance of care centered on the family of the child with cerebral palsy is evidenced (Vohra, Madhavan, Samdamoorthi, & Peter, 2014). Caring for a child with cerebral palsy is stressful for parents, especially the mother, because it requires intensive physical involvement, as well as dealing with emotional reactions to the child’s condition. The mother has different ways of adapting to stress and the demands caused by the child’s condition, making it necessary to use certain coping strategies such as resilience to stress, adjustment and adaptation (Nimbalkar et al., 2014).

In the Heideggerian view, care is a way of proceeding with the surrounding entities in the world - solicitude; care is what gives people the condition of humanity - human beings live the meaning of their own lives through care (Heidegger, 2017).

The mother faces difficulties in caring for the child because she does not know the best care strategies. The new demands contained in the family routine promote the restructuring of family relationships, as the child’s condition requires full dedication from one of the family members, who, in most cases, is the mother (Baltor & Dupas, 2013; Smeha et al., 2017).

It is essential the reorganization of the family’s existential project and the adoption of an authentic existence because it is believed that, in this way, the family will be able to take care of the child, attending to its needs, since they need to deal with daily multifaceted challenges of lifelong disability management (Vohra et al., 2014). Family adaptation, especially of the mother, is essential for the family to be able to provide care for the child.

It is in this delicate context that the professional nurse can act, offering information with the intention of directing the mothers as to the necessary care for children with special needs. However, it is important that the professional has theoretical/practical knowledge in order to provide subsidies capable of supporting this mother, resolving her doubts and reducing her uncertainties. The support provided to the mother can contribute to give new meanings to her ‘way-of-being-in-the-world’, helping her to offer/provide caring care to her child, geared towards its autonomy.

At the beginning, with the news of the diagnosis of the child, the mothers go through a state of shock, to later, gradually accept the situation: “Nowadays I take it easy, at first it was more complicated, because she didn’t walk either, it was very tiring, but as I told you, always with the support of my husband, then it was normal, I got over it” (M6).

> You know that, in the beginning, I was very angry, because I thought so, my God, even a rat, a disgusting animal, walks, why not my son? (crying) But then I started to think, think, think. Then we have to accept it, because if you accept it, it is easier to fight (M4).

The process of accepting the diagnosis of cerebral palsy requires time for the mother to understand what happened and develop strategies for care in this situation. As needs arise, new knowledge is required, as well as a family, institutional and social support network so that the mother can overcome this moment and accept the child's new condition.

The parents, but mainly the mother, when experiencing the bereavement process for the loss of the dreamed/desired child, feel guilty, consciously or unconsciously, for the child's condition for feeling responsible for the situation (Dezoti, Alexandre, Freire, Mercês, & Mazza, 2015). Ribeiro et al. (2016) conclude by saying that this feeling of guilt is intertwined with the feelings of sadness, disappointment and revolt for not having generated the child who had dreamed/idealized. Guilt is the main inhibitor of the happiness of these mothers (Nascimento & Faro, 2016), who still experience a moment of uncertainty, bereavement and fear (Santos, Marques, & Souza, 2017; Smeha et al., 2017).

In this sense, it is possible to observe when the mother says: "Then we have to accept […]", that this 'accept' was imposed on her. Once she understands that, when she becomes a mother, she is obliged to exercise care for her child, even if this is different from her projects, maternal care is socially understood as non-transferable, and cannot and should not be assigned to another person.

In this dimension, it can be said that maternal care for children with special needs is a unique and non-transferable experience. The emotions and feelings experienced with the birth of this child are described by mothers with great suffering, due to the intensity of care. Lima, Cardoso and Silva (2016) in a study on the impact of disability on the care relationship, claim that there is an abrupt interruption of dreams that affects emotional balance, in which the feeling of helplessness arises permeated by sadness and anguish, harming psychological well-being.

Becoming a mother is a long process, as the woman gradually builds her new role, that of being a mother. This process is influenced by the beliefs, values, dreams, senses and meanings that she attributes to motherhood (Pereira et al., 2014). As well as the senses and meanings that she attributes to her child's existence.

The mother M4 when saying "[…] my God, even a rat, a disgusting animal, walks, why not my son?" demonstrates her frustration in relation to her role as a woman generating a new being, as well as a feeling of guilt for not having responded to her future projects, with regard to motherhood. The feeling of anger hidden in the statement is strong, as the mother feels herself receiving divine punishment.

For Vargas, Maldonado, Scheeren, Brazuna, Spigolon, Maldonado, Barbosa and Pereira (2014), many parents of children with cerebral palsy justify the child's condition as a punishment, in an attempt to hold someone responsible. In many cases, the mother feels responsible for having given birth to a child with special needs.

According to Maldonado and Dickstein (2010), the fear of having a child with special needs can have its roots in childhood, when the being forms a basic image of itself as a good or bad person, and these feelings can manifest themselves through the punishment of having a disabled child.

In this sense, in order to overcome this unexpected demand, the mothers report having become attached to God. Religiosity and faith in God are shown as a support to sustain their lives in facing the situation, making them winners of the challenges. "First, I got attached to God. Faith in God" (M8). "Despite everything, we never lost our faith, our faith in God was always great" (M1). "I havefaith in God" (M4).

The testimonies describe faith in God as a way of helping to overcome/adapt the mother's new existential itinerary as the child's caregiver. Sandor, Marcon, Ferreira and Dupas (2014) affirm that, regardless of the type of religion they refer to profess, faith in God is a factor that gives strength to go on life, act as a foundation to overcome the diagnosis, accept the condition of child and believe in the improvement of the child.

Faith in God was and is fundamental for mothers to acquire strength to take care of their child, to believe and to fight, overcoming the difficulties experienced on a daily basis, producing feelings of hope and acceptance. Hope combined with faith in God is part of the daily lives of these caring mothers. Spirituality encourages the family and produces feelings of hope or acceptance of the situation imposed by the child's condition.

The 'being-in-the-world' of the family undergoes many transformations, mainly that of the mother who starts to dedicate herself almost exclusively to the child. The diagnosis generates uncertainty, a fact that makes the family, especially the mother, seek the spiritual dimension based on faith and hope (Dezoti et al., 2015).

It was also possible to notice in a statement that the participant uses her spiritual perspective as a form of explanation for having experienced the fact of having a child with cerebral palsy: "God does not give you a burden you cannot bear. Have you ever wondered if God gives a child like that to a cruel mother? What would become of a child like that?" (M4).

The statement of M4 can demonstrate a defense mechanism used by this mother, with regard to confirming her ability as a woman to generate and as a caring mother, as she states that God only gave her a child with this special condition for believing in her maternal competence.

It is worth mentioning the philosopher Roselló (2009), who argues that caring requires intuition and sensitivity, which is not only configured in the development of a technique, but fundamentally in artistic creation. At the moment of acceptance, the bonds between mother and child are strengthened, the feeling of love overcomes the painful experience: "He is everything to me (crying / silence)" (M8). "Today I thank God that he is with me. It doesn't matter if he's special or not. All I ask for God is to let him always with me, my little companion" (M9).

Caring in this sense is related to the task of edifying, that is, rebuilding the person again from its foundations (Rosseló, 2009). In this sense, it appears that mothers have rebuilt their way of living and seeing the world. This change/adaptation is significant, to the point that mothers report asking God to leave their children, to whom they dedicate their life, always with them.

The mother and caregiver, after experiencing the phase of bereavement, which is the loss of the projected/idealized baby, begins to adapt to the new being, starting to live to the children and for the children:

> For me, well, for me it's normal, we know everything. Dealing with him, God gives us a gift, we can't even explain where so much wisdom comes from to understand him in everything. I understand him at all, when he is not well, when he is well, when he wants something and when he does not want it (M2).

> I don't live without him. He is the reason for my living. We get so used to it that when I had to pay a bill [...], I go with my heart in my mouth, because I know that if he wants to take a sip of water, I have to give it, if he is going to eat, it is me who has to give, because if not, he doesn't eat (M4).

As can be seen in the testimony of mother M4, the care and dedication make her not imagine life without him, making him the center of attention of her life when she says: "He is the reason for my living".

Someone’s reason for living is the authentic way of existing and coexisting, of relating, of being present. It is in this coexistence and interaction, in this game of relationships that the human being builds its own being, its own identity. It is a way of ‘being-in-the-world’ for care, which always accompanies the human being, because it will never stop caring and unveiling itself for someone (Boff, 2014).

In a study with the objective of analyzing care based on the experience of mothers who care for children with cerebral palsy, with Heidegger’s hermeneutics as a theoretical framework, the results demonstrated that the process of caring of mothers can be approached as a way of being in which there is the possibility of an encounter with the self in care, a moment when mothers assume the authenticity of care (Pereira et al., 2014).

At this juncture, it can be said that these mothers act in a way of ‘being-in-the-world’ to care for their child; however, it is understood that for the mother to take care of herself, she needs a structure both inside and outside, that helps to build her autonomy. Thus, not only the family, but health professionals can serve as support, understanding that the situation requires constructive support, helping to restructure the ‘being-in-the-world’ of the mother and caregiver of the child with special needs.

Simões, Silva, Santos, Misko and Bousso (2013) developed a study with family members of children with cerebral palsy and concluded that these family members need professional support, who know the social, economic and cultural aspects of the family, in order to provide care not only to children, but also to parents, who can also get sick in the face of the difficulties that make up this experience.

It appears that the caregiving mother manifests a ‘way-of-being-in-the-world’ of care, establishes an approach and bonds with the child, being able to understand the child’s non-spoken language. Understanding the other through the unexpressed requires a relationship of subjectivity and intersubjectivity, that is, to be present in the life of this human being. Communication has multiple facets, in addition to the language of speech, permeates meanings, feelings, among others, sometimes not perceived.

The ‘being-in-the-world’ in relation to the other uses different ways of communicating (Heidegger, 2013). The child’s/adolescent’s mother has the ability to understand language, in its various shades. This understanding is constituted by intersubjectivity, coexistence from day to day, being possible to communicate without mentioning words. In the Heideggerian perspective, human beings have the ability to communicate even in silence, because the important thing is not the language spoken but the meaning that is attributed to it (Heidegger, 2017).

To take care of someone is to understand him/her. In this case, the mother’s care for the child involves attributes such as attention, zeal and dedication. Living the phases of the loss of the dreamed child and relearning to live with the new being in a different condition is part of unveiling the being of this mother.

The caregiving mother, after experiencing this existential facticity, begins to reorganize her ‘way-of-being-in-the-world’, to dedicate herself to the child. They understand the child even before it can demand an attitude of care that causes restlessness, concern and a sense of responsibility. In this sense, care is the foundation for all human life, it is from it that we understand the human being, since it arises from the moment when someone’s existence makes sense to me (Boff, 2014).

The mothers of the study dreamed of being mothers, however, they did not imagine that the child would come differently from the projected/idealized. When experiencing the initial shock of the diagnosis, mothers begin to (re)adapt to the new situation, that is, the loss of the dreamed child and the acceptance of the real baby, who developed special needs.

## Final considerations

It was found that becoming a mother of a child with special needs requires a continuous adaptation process based on the child's developmental stages. Moreover, it was possible to understand the woman's existential itinerary from the pregnancy of the dreamed/projected child, the birth of a different child, the shock to the adaptation to the new being, understanding the peculiarities of each phase experienced by her. After adaptation, mothers start to live to and for their children, making them the center of attention of their lives.

When rethinking the proposed objective, it was understood that the study instigates to advance in the intention of creating strategies that help caregiving mothers, to perceive themselves as 'being-in-the-world'. It is expectedto contribute to a problematizing reflection by health professionals regarding the need for family, institutional and social support networks, as well as about the role played by health professionals in direct and indirect assistance to the family and in especially the mother.

It was understood that the social demand is evident, there is a need for comprehensive and humanized assistance to the mother in order to understand it in the phases that make up the process of adapting to the condition of mother of a child with cerebral palsy.

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