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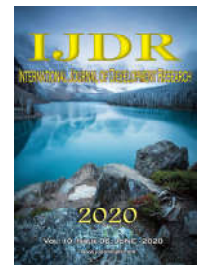
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RESEARCH ARTICLE

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## THE PROCESS OF ADAPTATION OF MATERNITY / FATHERHOOD IN THE CARE OF CHILDREN WITH SPECIAL NEEDS

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### ABSTRACT

This study is guided by the following question: How is the process of adapting parents to care for children with special needs? In order to answer this question, we aim to: describe and analyze the adaptation process of parents in relation to the care of children with special needs, and it is justified by the importance of the possibility of raising discussions and improvements in care proposals for the population of research study. This is a qualitative case study. The sample consisted of a couple of parents with a child with special needs, living in Arniqueiras - Distrito Federal, Brazil. Data collection was carried out in the 1st semester of 2019. When parents receive a diagnosis of a child with special needs, they go through periods of conflict, as caring for their children requires changes in the whole family routine, making parents often feel tired and overwhelmed. Parents of children with special needs need a welcoming and comprehensive nursing, nursing interventions based on Callista Roy's adaptation model allow nurses to fully understand the family's needs, promoting their adaptation within the four adaptive modes, maintaining effective behaviors and intervening on ineffective behaviors. By conducting this study, we were able to understand that the adaptive process of parents of children with special needs happens differently from parents who do not have children with disabilities, because the news of a disability comes with the frustration of a dream and all the planning that one day it was realized, it is interrupted and new plans and roles are adopted for the arrival of the child.

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### INTRODUCTION

Motherhood is a unique event in the woman's life, the way each of them experiences this moment depends on the context in which they are inserted. The experiences, desires and expectations are different for each one. Motherhood is not only related to physiological changes, it involves dedication, care and emotional involvement between mother and child (PICCININI, et al., 2008; CORREIA, 1998). Having a child is seen in different ways by society and can be considered as a dangerous, painful, interesting, satisfying or important experience for a given woman.

The way women experience motherhood is something very personal, and it is not only associated with individual characteristics, but also the personal history of each one, the opportunity for pregnancy, their desire in relation to the child, the relationship with the father and also with social and cultural factors (CORREIA, 1998). Traditionally, women have been considered to be primarily responsible for feeding and protecting their children, in addition to domestic commitments (MURARO, 1995). Motherhood was seen as mandatory for all women, regardless of social class (VIELLA, 2015). Historical changes began to take place in the 19th century concerning the possibility for women to express themselves more in terms of their wishes and choices.

At the end of the twentieth century, the discovery of birth control pills and the spread of contraceptive techniques allowed women to become responsible for their fertility / fertility, as soon as women have greater freedom and motherhood is no longer seen as an obligation and rather as a choice (RESENDE, 2017). The option of having or not having children, no longer depends exclusively on the woman, the traditionalist view that the woman should be more responsible for the child in relation to the father loses space in the face of new family models (RIOS; GOMES, 2009; VIELLA, 2015). With this new family model, paternity also ended up changing and with that the father figure became more active in the lives of children. The changes in the family, in which it brought the possibility that the woman was no longer restricted to the home, enabled the father to assume new functions. However, paternity for a long time had its role disregarded in the context of child development. In which the man was considered the main responsible for the financial aspect of the home and the other obligations were imposed on the woman (BERNARDI, 2017). Rodrigues (2016) brings as a concept of paternity what involves the constitution of values, the uniqueness of the person and his human dignity, acquired mainly in family life during childhood and adolescence. According to Bernardi (2017), there is still questioning about the real paternal role in today's society, since old concepts about women being more qualified to be in charge of child care, still persist. When talking about pregnancy and birth, it is understood that they constitute phases of change for women and men, with transformations and uncertainties that accompany the acquisition of new roles and responsibilities that did not exist before. Thus, paternity and motherhood can be mediated by conflicts determined by the new situation that the couple experiences (FREITAS, 2007).

The birth of a child produces several changes in the family context, when it comes to the arrival of a new member there is a process of very significant emotional significance (OLIVEIRA, 2018). According to Batista and França (2007), parents are already beginning to plan, dream and fantasize about the arrival of their children even before they are born. It is normal for these fantasies to meet the standards of normality established by our society, standards that highlight the perfect, the healthy, the beautiful. The mother already creates in her thoughts an image of the child huddled in her lap with characteristics that are familiar and attractive. The father, in turn, already begins to imagine his son running, flying a kite and playing ball. In view of all these plans made by parents in relation to the child to come, it is difficult to think about the possibility of having a child with some type of disability, disability is not something desirable and is out of all planning. And this is not the fault of the parents, but of a society that most of the times sees the disabled as someone extremely different from what is advocated as "normal". Given this context, it is possible to imagine that the possibility of having disabled children is not addressed in future parents (OLIVEIRA, 2018). The arrival of a child with a disability generally makes the event quite traumatic, bringing a family imbalance, as it is a time of great changes, doubts, and uncertainties (TRINDADE, 2004). The diagnosis of a disability brings an idea of death, a death that most of the time is not real, but symbolic. Death of the plans, dreams and projects that had to do with that child. It is what we call the grief of the idealized child, the grief of the parents usually mixes with feelings of anger, guilt, self-reproach and a feeling of being wronged (VENDRUSCULO, 2014).

The adaptation of having a child with special needs happens slowly and gradually, it is a complicated and permanent process, as from the diagnosis, families experience an intense change in their daily lives, considering that, exercising the role of mother and father of a child with special needs, it presents itself as a new role, which needs to be learned (GENERALIS, 2007). In this sense, there was an interest in applying Callista Roy's adaptation theory and nursing care to parents of children with special needs, with a view to contributing to their adaptation. Callista Roy and Andrews (2001) establish as a nursing goal the promotion and adaptation of the person in the four adaptive modes: physiological, self-concept, interdependence and role performance. This study is guided by the following question: How is the process of adapting parents to care for children with special needs? In order to answer this question, we aim to: describe and analyze the adaptation process of parents in relation to the care of children with special needs, and it is justified by the importance of the possibility of raising discussions and improvements in care proposals for the population of research study.

## METHODS

This is a case study. The sample consisted of a couple of parents with a child with special needs, living in Arniqueiras - Distrito Federal. Data collection was carried out in the 1st semester of 2019. The inclusion criteria were: parents of children with special needs under 10 years old and those who did not fit the inclusion criteria were excluded. The interview was conducted through a semi-structured script, composed of open-ended questions about physiological, psychological, social and spiritual aspects, lasting approximately 30 minutes, recorded through voice recording and later transcribed for better data analysis. To maintain the interviewees' privacy when transcribing the speeches, the names of the parents were replaced by (Mother and Father) and the names of the daughters by Letters, with the child with special needs being K and the sister being C. The data obtained were analyzed using the technique of discourse analysis (Orlandi, 1999). In a table, a nursing care plan was carried out on top of the ineffective behaviors identified in the interview. This study was carried out according to the ethical principles of resolution 466/2012. The interviewees' participation was carried out voluntarily, by signing the Free and Informed Consent Form (ICF). The present study was approved by the Research Ethics Committee of the Euro American University Center - UNIEURO, registered under n° 3.310.088 and CAAE n° 09073019.4.0000.5056.

## RESULTS AND DISCUSSION

Parents of children with special needs go through a long process of adaptation, caring for their children requires changes throughout the family context, bringing an imbalance in the entire organizational structure of the family, generating fears, doubts and uncertainties (MILBRATH, 2008). Nursing plays an important role in the process of adapting parents to care for their children, both in terms of health education and in implementing care focused on the whole family, helping them in this new journey (BARBOSA; SILVA, 2007). According to Callista Roy's adaptation model, the person is seen as an adaptive system, constantly responding to stimuli from the internal and external environment. These stimuli are characterized in: contextual and residual focal points (ANDREWS; ROY, 2001). Focal stimuli are the internal and

external stimuli that most confront the individual, in this study we can characterize the birth of a child with special needs as a focal stimulus. The contextual stimulus, on the other hand, comprises all the other stimuli present in the situation that contribute to the effect of the focal stimulus. In relation to the residual stimulus, this can be described as the beliefs, culture, values of each family and each person individually (ANDREWS; ROY, 2001). Through stimuli received, regulatory mechanisms are activated in order to trigger responses that are classified as adaptive or ineffective. These responses are called behavior and these behaviors can be observed within the four adaptive modes: physiological, self-concept, interdependence and role performance (ANDREWS; ROY, 2001).

### Adaptive physiological mode

The physiological mode is the physical responses to the stimuli of the environment and involve the five basic human needs: oxygenation, nutrition, elimination and balance between activity and rest (ROY; ANDREWS, 2001). When parents receive the diagnosis of a child with special needs, they go through periods of conflict, as caring for their children requires changes in the whole family routine, making parents often feel tired and overwhelmed. The care provided at home implies a continuous journey with diverse responsibilities and tasks, bringing in fact an imbalance in their basic needs as noted in the speech:

*I sleep less, I sleep a lot less we feel overwhelmed, you know ... a lot of things happening. (Dad). Staying at home and taking care of the children and even more in this situation, tires you more than you go out and work. (Dad)*

Some children with special needs need continuous care at home, as some leave the hospital with devices necessary for their survival, as in the case of the child under study. Home care is seen as an option for these families, as it allows comprehensive care in locus. A multidisciplinary team is directed to the care of the child according to their needs and the family starts to assume the role of primary caregiver (SILVA, et al., 2005). With this new role that most of the time are attributed to parents, they need to organize themselves in order to meet the needs of the child, with this the parents give up their social lives in favor of caring for the child.

*Home care they require you to have a caregiver, you have to have someone responsible 24 hours, so it is very complicated for you to think about a routine with exercises ... being that you are the caregiver. (Dad)*

Data analysis allows us to realize that parents find it difficult to reconcile other daily activities in caring for their daughters, such as the practice of physical activity leading them to a sedentary lifestyle. Sleep pattern disturbance was also observed in the analysis. How family members respond to the stimulus received will depend on the context in which they are inserted, and especially, the support network they receive. Support networks are the main mechanisms used by family members in order to achieve efficient adaptive responses, when experiencing this process (MILBRATH, et al., 2008). Nursing, being closer to the patient and his family consequently ends up having a greater knowledge of their dysfunctions, being able to contribute to coping in this way. Then, during the process of adapting the physiological mode,

nurses must know how to seek instruments and strategies to assist in care. By knowing the ineffective process that the family member faces as a caregiver, the nurse can provide a more accessible way to achieve adaptation, contributing to a better quality of life. Ineffective physiological problems must be investigated and evaluated in order to be able to know what triggers them and thus be able to act with priority interventions for this mode (QUEIROZ; JORGE, 2006).

### Self-concept adaptive mode

The self-concept is related to the psychological and spiritual aspects of the individual, in this way he seeks the psychic integrity of the Self and is subdivided into two categories: the physical self in which his body image is related and the personal self that he refers to. self-awareness, the ideal self and the moral-ethical-spiritual self (ROY; ANDREWS, 2001).

Body image is not something definitive, as it is constantly changing, changing according to the influence of emotional states, psychic conflicts and contact with the world and other people. Disorders in body image can alter the individual's self-esteem, Roberts and Monroe (1994) affirm that a low self-esteem is related to emotional factors, stress and interpersonal conflicts that, consequently, can trigger a picture of anxiety and depression (BITTENCOURT, et al., 2009; COPATTI, et al., 2017).

*Currently I'm in my worst phase ... I've always been very vain so now it's the most difficult phase, I believe that everything, the routine, staying at home, being the mother of a special child, you get a lot, how do I talk? Underestimated you know? (Mom)*

*I feel my self-esteem very low, it is the worst phase. (Dad)*

Parents of children with special needs experience a high emotional demand, since the task of caring for a child with a disability brings with it a feeling of helplessness and incapacity (MOREIRA, et al., 2015; AMIRALIAN, 2003). The uncertainty of the child's development, prejudice, fear of the future and the deprivation of the parents due to the routine of caring for the child, reflects on their low self-esteem, causing damage to their psychological health over time. Brazelton and Cramer (1992) believe that the biggest problem caused by the birth of a disabled baby consists directly in the mother's self-esteem imbalance, as the child is seen as a reflection of maternal failure, which can modify the bonding process between mother and son. In stressful situations experienced by the child's disability, families seek to approach religious institutions or religiosity in an attempt to receive answers to their questions or in the search for emotional support that facilitates coping with difficult situations (BOUSSO, 2011).

*From time to time I despair and think: my God this phase is not going through, it's kind of a roller coaster ... it's difficult (Dad). In religion we find support ... we do a Bible study I think that was very important, it helped us in coping (Mother)*

The analysis of the data allows us to perceive that the family under study finds comfort in facing difficult situations in religion, however the psychological aspects deserve attention in relation to body image disorders and the low situational self-esteem reported by both. At this stage, it is important that nurses understand the family in its entirety, seeking to

understand all its dimensions, promoting physical, emotional and spiritual well-being (INOUE; VECINA, 2017). Barbosa and Silva (2007) highlight that the human being is not limited only to biological aspects, but as someone with biopsychosocial and spiritual needs. Promoting comprehensive care leads us to move towards the humanization of care.

**Adaptive paper performance mode:** The role function mode addresses the roles that the person occupies in society as primary, secondary and tertiary. The basic need in this way is social integrity. Roles are classified into: primary, which are determined by the behavior that the person assumes during a period of life that are defined by age, sex and stage of development. Secondaries are those that the person takes on to complete the tasks associated with the stage of development and the primary role. The tertiary is temporary, and can be represented by hobbies (ROY; ANDREWS, 2001). In general, most families have well-defined roles with their own rules and values, so that all members know their roles and know how to play them. However, unexpected changes mainly in relation to the disease in any of its members may require a redefinition of roles and the learning of new rules and values in order to adapt to the new lifestyle, summarizing, with each new impact event experienced by them must be restructured (BUSCAGLIA, 1997).

*I think motherhood is challenging in any way, you rediscover new roles that you haven't seen before. (Mom)*

Exercising the role of parents of a child with a disability is seen as a new and complex role. The interviewed family demonstrates through the speeches the great impact they had when they got home with their daughter, mainly because she is "technology dependent". According to Siqueira, Reis and Pacheco (2017) this term is used to describe who needs a device to compensate for the loss of some vital function of the body.

*When she came home I was very insecure about everything, because she has a device and it scares ... we were afraid to touch her a lot. (Mom)*

With the child's arrival at home after a long period of hospitalization, parents assume responsibilities and develop skills to perform often complex procedures in order to meet the child's needs and maintain their well-being. However, this is not an easy task for families, who often find themselves confused in their role as professionals and family members. Even if the family has a home care service, as in the case of the child under study, what is perceived is that the family feels the need to get involved in caring for the child, as this is often the way she finds to feeling closer to the child (FRACOLLI; ANGELO, 2006). The presence of home care is immeasurable for the family, as it allows the presence of a specialized team to provide essential care for the survival of the children. However, the entire environment needs to be transformed, which was previously a space of tranquility and coziness, now comes to be seen as a hospital extension, bringing a mischaracterization of the home, due to the continuous presence of health professionals, equipment and procedures that need to be performed. to meet the child's needs (FRACOLLI; ANGELO, 2006).

*I was going to talk about the shock that is home care, which inside your house suddenly seems like it's not your*

*home, right ... and with that you lose a lot, lose privacy, lose, it's hard, until you get used to it. (Dad) There have been times when I cried and wanted to wipe out all her devices, and get all these people out of my house. (Mom)*

With the countless changes that have taken place in the family's life, another important fact to note is the tendency that parents have towards social isolation, due to the continuous nature of caring for their child, opening up badly for social life, work and even leisure (SILVEIRA; NEVES; PAULA, 2013).

*We both worked, (mother) was fired, so she is at home right now ... the routine revolves around K.'s Home Care (Father)*

*I stopped studying, there are many things that influence. (Mom) We hardly go out ... we went to the cinema once. (Father and mother)*

The analysis of the data allows us to realize that the parents feel confused and tense with their new role due to the changes experienced, the lack of privacy is also highlighted by them with the continuous presence of health professionals in the home environment. Social, professional and leisure life is neglected because parents often live the life of the child. Fear and insecurity are also highlighted by parents when they have to perform complex procedures. The home visit of the nurse must be carried out in such a way that the parents do not feel invaded, but supported. The nurse needs to create a relationship of trust with the family in order to know their needs, guiding and training them in the procedures and techniques to be carried out with children in order to make them safer, reducing the feeling of fear of disability. It is important to know that the quality of life of children with disabilities is directly linked to the physical and psychological state of their caregivers. Therefore, nursing actions must cover all family members.

#### **Adaptive interdependence mode**

The mode of interdependence refers to interpersonal relationships, that is, in interactions in giving and receiving love, respect and value through relationships with other individuals that represent importance to the person and support systems represented by people, groups or communities that contribute to satisfy the need for it. The basic need for this adaptive mode is to relate to a feeling of security in nurturing relationships, which is called affective adequacy (ROY; ANDREWS, 2001). Interdependent needs are achieved through relationships with others and in a crisis situation, interdependent relationships are subject to change, which can contribute to solving the problem or, on the other hand, making conflicts bigger and resolving more difficult (MELO; SILVA; FERNANDES, 2005). The birth of a child with special needs can be highlighted as a crisis situation, as the parents go through a period of shock, after sadness or anxiety, and then, gradually, the child's acceptance occurs. If the birth of a child in normal conditions generates many changes in family life, great challenges arise in social and interpersonal relationships with the birth of a child with a disability (ALVES; COSTA, 2014). The discovery that the child will have a disability is experienced by the parents as a moment of mourning, as the loss of the idealized child occurs, since during pregnancy the parents dream and make plans for the child and when they realize that the reality of that child son

will be totally different from what was once dreamed this reality disturbs the psychic stability, which in turn, can affect the family dynamics (ANDRADE, 2015). When faced with such a circumstance, parents need to adapt to the new reality, however they feel frustrated and unprepared to take care of their child with special needs, as seen in the speech:

*A gente não é preparado tanto culturalmente como de informação, a gente não é preparado pra ter um filho diferente, mas você vai se descobrindo dentro da sua realidade então é desafiador, mas é gratificante sim, eu amo demais minha filha da mesma forma que eu amo a C. (Mãe)*

In general, parents do not feel prepared to face this clinical condition and end up not knowing how to proceed in this care, given that they need much more support systems to achieve adaptation. Support networks can be composed of grandparents, uncles, siblings, neighbors and friends who are the people who contribute to the achievement of an affective fit, in which they help to reduce the stress of parents, when they become company when they are available to listen, advise, assist in tasks, reducing suffering and feeling of helplessness.

*A rede de apoio que a gente tem é amigos que também estão sempre nos apoiando. (Mãe)*

However, just like parents, other family members also feel insecure in relation to the child, as they do not know how to act in certain situations and often feel fear related to the devices used by the child. As it is a reality little known to everyone, family members also go through the adaptation process, which can take time, causing, therefore, the removal of those who were once close.

*The family was kind of scared a lot, but people very close to us are afraid, afraid to hold K. in their arms. (Dad)  
Even if you are surrounded by family members (...) people are afraid, afraid, it is difficult. (Dad)*

When analyzing the statements, it was observed that the support network that the couple receives comes mainly from the circle of friends, who are always supporting them and keeping close to both the parents and the child, thus being an extremely important aspect for the family that is in this situation of conflict, as it represents a fundamental point of support for the growth of the couple and for the formation of adaptive responses, proceeding in making positive decisions and, consequently, transformations of ideas and behaviors.

Nursing, in turn, must be prepared to offer support to the family, clarifying their doubts by listening to what parents have to say. It must transmit information about the resources and services available to the family, and the intervention strategies aimed at the child and the family, be welcoming and understanding so that they do not lose hope (DANTAS, et. Al, 2010). It is important to emphasize that nursing should not limit the child to a being with special needs, but teach parents to value the achievements achieved, because when they see beyond the child's disability, the feeling of sadness and grief are replaced by joy and happiness. Therefore, nursing care needs to go beyond the child's limitations, but see the family as a whole helping to achieve adaptive processes in order to make them adapt to this situation (PIMENTAEL, 2005). The limitations found for the construction of this study was the low

amount of theoretical bases, related to care aimed at parents of children with special needs, much is found in relation to care for the disabled, however there is this limitation in care aimed at children. Family that is the key to success in child care.

## Final Considerations

The research satisfactorily achieved the proposed objective, it was possible to describe and analyze the adaptation process of the parents in face of the care of the child with special needs. It was observed the difficulties found by the parents in adapting to the changes that occurred after the birth of the daughter with a disability. Parents of children with special needs need a welcoming and comprehensive nursing, nursing interventions based on Callista Roy's adaptation model allow nurses to fully understand the family's needs, promoting their adaptation within the four adaptive modes, maintaining effective behaviors and intervening on ineffective behaviors. By conducting this study, we were able to understand that the adaptive process of parents of children with special needs happens differently from parents who do not have children with disabilities, because the news of a disability comes with the frustration of a dream and all the planning that one day it was realized, it is interrupted and new plans and roles are adopted for the arrival of the child. In this way, we perceive the great importance of using the adaptation theory as a guide for the practice of care because, when studying this theorist, we are able to evaluate the unsuitable processes that the parents of this child with special needs have been going through and on top of that plan interventions that help them in the everyday life and taking care of the daughter.

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