

# Instability of Roles Between the “I, Woman” and “Being Mother” of a Disabled Child

ORIGINAL

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## Abstract

**Objective:** To reveal the new roles assimilated by the mother in caring for a child with a disability.

**Method:** A qualitative study, comprehensive and interpretative, guided by the method of Oral History Thematic. It was held in the city of Timbaúba-State of Pernambuco, in the months from June to August 2013, at the Association of Handicapped Friends of Timbaúba (ADAT). The understanding of the empirical material was conducted by the technique of thematic content analysis.

**Result:** Based on the narratives of the six mothers became perceptible the annulment process that these women faced throughout their lives, to devote themselves to the care of their children and who made the obstacles a motivation in their lives to reach the stage of acceptance.

**Conclusion:** Attention to the need of strengthening strategies for inclusion in community mental health policy as an example of Community Integrative Therapy to host and care of mothers of children with disabilities.

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## Introduction

The phenomenon of pregnancy produces naturally in the woman a physical, mental and social transformation, whose effects can bring reflections about the biological act that her body has to generate another life, as well as on the challenges being faced, such as to rea-

## Keywords

Mother-Child Relations;  
Disabled Children; Maternal  
Behavior.

range her life from motherhood. This phenomenon causes changes in the body that merge with the fear of the invisible, but still noticeable, set of sensations, involving the fruit of a pregnancy.

Study shows that trying to manage motherhood and life can cause conflicts and points out that the belief of the mother as the only capable of taking care of the child brings feelings of anxiety and dissatisfaction in women. These conflicts are attributed to the fact that being a woman has always been associated with maternity. However, socially, this relationship has been changing throughout history. [1-2]

One can see that, for the woman, the meaning of being a mother permeates a context of responsibility and protection from conception. The commitment to carry a pregnancy to term promotes a personal formatting on woman who stumbles upon the singular moment to gestate a new and later give birth to this that will always be her child.

In contemporary times, even with the freedom of several choices that the woman had taken maternity, it still seems a very important phenomenon, and when the right to accept children is denied by the biological impossibility, many women resort to adoption process, in order to realize the desire to have a son. [3]

The woman inserts in the motherhood project hosting a life in her body and at the time of this confirmation it consumes, even imperceptibly, futuristic expectations that during pregnancy can be frustrated. In this context, the possibility of conceiving a child with disabilities and abruptly meet a reality that wasn't ready.

The woman is imbued with greater responsibility for child care, be it healthy or with some type of disability. Our society, culturally, asks from the woman her role and the responsibility for generating an exacerbation of home tasks to this woman. The birth of a child with disabilities brings a series of familiar consequences, in that mother often assumes alone the care with the disabled son, taking emotional and affective consequences for her. [4]

It notes that the impact of the presence of a disability in children tends to be greater than the bigger are the expectations about the birth of the child and that when parents are informed, at the time of birth, the child have any disabilities, birth happens to represent a moment of sadness, despair, confusion and fear. In these circumstances, can emerge conflicts involving a difficult acceptance on the part of the family, and from that moment begins to experience ambivalent feelings, such as love and hate, perfect and imperfect, accept and reject. [5]

The counter sentimental before the birth of a child with disabilities generates sudden transformations in family structure, which leads to a reformulation of roles and a readjustment of feelings. Therefore, it is considered appropriate to promote scientific approaches from boarding in public policy issues, social and health, in which the woman is positioned as the protagonist in a scenario where she also needs to be taken care of. It is extremely important to penetrate in the world suffered from mothers who lament and chose to help children weakened and fell asleep the desires and designs to life. [6]

Before this, the following question arises: How do the changing roles of the mother about the new reality of having a child with a disability? In order to get answer to this question, this study was developed, which consists of a cut of a dissertation, where the survey was observed this phenomenon that caught the attention of authors and, therefore, the need for a distinctive look for the mothers.

Despite this fact, the knowledge of the new roles of mothers of children with disabilities pointed out important signs to understanding health actions that are offered and the planning of new health practices by setting a relevant theme, from the social point of view, for contributing to the quality of health care in the case of the caretaker, the mother and the person with a disability. The scientific and professional point of view, the study brought through a brief synthesis of the knowledge produced with some aspects that encompass the theme, an update of health professionals and the

academic community and the promotion of further research in this area.

For all that, the objective of the study reveals new roles assimilated by the mother to care for a child with disabilities.

## Methods

This is concerned as a qualitative study, comprehensive and interpretative, guided by the method of Oral history (HO), more specifically, the Thematic Oral history, whose goal is to clarify the narrator's opinion about any events defined, investigated the experience of being a mother of a child with disabilities. [7]

This study was conducted in the city of Timbaúba, PE, in the months from June to August 2013, at the Disabled Association Friends of Timbaúba (ADAT), a philanthropic institution, reference to the treatment of impairments for children aged 0 to 16 years old, but that receives special cases, according to some internal criteria. The period of data collection, the institution had joined 80 children with disabilities.

The choice for the institution, while a search scenario, due to the fact of being the place where mothers bring their children to neuropsychomotor rehabilitation. For the study, the colony was constituted by the mothers of children with disabilities who frequented the ADAT, which were randomly selected at the time the institution to attend meetings with group of mothers or for children attendance. Therefore, the network was formed by six mothers who accepted and had a position to participate in the study.

To make possible the empirical research, there was elected as an instrument the technique of the guided interview, with cohort questions, defined as questions that relate to all the interviews and must relate to the target community, constituents of group identity. [8]

The interviews were previously scheduled with the collaborators, being written with permission of the participants. The whole process was guided by

three steps: the pre-interview, the interview itself and the postinterview, to build coherent discourses.

In Oral History, they are included as contributors to the project. It can be set to the name of the respondent, which has an active role in the history and cease to be mere informant, actor or search object, and establishes a relationship of commitment between the parties, then, subject of the research. [9] The OH considers the deponent as a collaborator, with freedom to speak about his personal experience and participate in the entire process. [10]

The analysis and discussion of the documentary corpus happened after textualization, postinterview step when it picks the original text, leaving the more cohesive and structured, from a thorough reading for understanding the lived, the language and the senses expressed. There was identification of vital tone of narratives, which guide the construction of thematic axes, on the basis of the objectives proposed in the research.

Understanding the empirical material was conducted by thematic content analysis technique, which consists in finding out the cores of meaning that make up a communication whose presence or frequency as meaning something for the analytical object in question. [11] This analysis provided the triangulation of the data, from which the analyst performs an interrelationship between his perceptions, the material produced (documentary corpus, vital tone and thematic axis) and the relevant literature, in order to deepen the look about the phenomenon investigated.

In the process of investigation, there were adopted the ethical observances included in the guidelines and in the rules of the Resolution 466/12 of the National Health Council. [12] The research project has been approved by the Research Ethics Committee of the Health Sciences Center of Federal University of Paraíba (CCBS/UFPB), being approved on the day 6/18/2013, under the CAEE 14725013.0.0000.5188.

## Results and Discussion

Within the family context, the mother represents a person who provides comprehensive care and does everything she can to provide the best to her children, especially when they have some kind of disability.

This mother, culturally, exerts her role of caregiver, often giving up her social and professional lives in order to contribute to the best and healthy development of her children. [13] The discovery of the diagnosis of a disability in childhood is a strong emotional impact event for mothers and can mean to them a loss, of a healthy child. [14]

The analysis of the speeches of the collaborators showed that the instability and roles assimilated by the mother to care for a child with disabilities directly influences some areas of her life. The empirical material enabled drawing some thematic approaches presented, analyzed and discussed below:

### Influence on self-care and on the social-affective relations

Mothers show, in their speeches, a fragile self-care because of the difficulty of finding a time to care for themselves and relate to other people, as demonstrated in the following statements:

*[...] nobody sees how tired I am during the days, I go to ADAT, swimming, school, then, at night, I want some time just for me, to get some rest, talk to my friends, refresh my mind.*

Krysslane.

*My whole week was exclusive for Débora [...], because I used to travel every day, sometimes I did my services during the night, I had no time, sometimes, I came back from Recife, when I got home, Took a shower and laid down, she started to cry, cried a lot.*

Rejane.

*[...] I spent nights and nights without being able to sleep with him [...] there were lots of sleepless nights to take care of him, I didn't sleep to keep looking after him and wondering when a crisis would come again.*

Marilene.

It is worth reflecting that the devoted mother's theory was rather questioned from the 60's by the feminist movement, which first emerged in the USA and spread to other Western countries. With that movement, women started to share the care of her child with her partner without completely departing from those tasks, only seeking to reconcile the maternal (home, interior) and female (work, exterior) roles. [15]

Although nowadays there is a greater division of care among family members, this is still centered on the mother, who, in addition to provide care to family and home, also needs to be constantly vigilant to meet the needs of her child with disabilities and the demands arising from such condition. This accumulation of responsibility can trigger a condition of physical and emotional instability to the mother.

It is noteworthy that, in most cases, parents seek other diagnosis that may go against the initial finding of disability, being common the consultations with various specialists. Nevertheless, with the arrival of the disabled child, they abdicate the plans for the future and begin the search for meaning to this new existential situation. [16]

One observes in the reports that the ongoing care of these mothers to their children in an environment with constant stress, loss, sadness and fatigue, can result in an emotional wear, an emotional overload of work, leaving them vulnerable to mental illness.

A study with 75 mothers of children placed in two groups - mothers of typical-developing children and mothers of disabled children - showed that most mothers of both groups are stressed.

It also observed that more than 70% of participants from both groups are in the resistance phase. One estimates that the result indicates a potentially stressful lifestyle of those women, to the extent that, regarding the stress phase, one knows that the person will come out from one phase to another worse one, if he/she is not able to get strong to cope with the stressful situation, or if it is not removed. [17]

### Influence in academic life and professional career

Mothers show constant conflict because they abdicate their personal projects to live according to the lives of their children, which requires complete care, zeal, devotion, resignation, acceptance and overcoming on the difficulties encountered in daily life.

In the speeches of the collaborators, it is possible to identify the changing of roles and the dedication of their lives to take care of their children:

*I had to leave desperately, the work careers, because he cried a lot, so I left everything incomplete [...]. That's when I've lost my job and decided to take care only of him. Actually, I live, practically, just for him in this life. My purpose is to take care of him!"*

Marilene.

*My life is in that kind of routine, just for my daughter, I can't work, study and so much other things I can't do [...] Will I ever be able to live my life, will I ever move forward with my life? I'm 24 years old now [...]"*

Krysilane.

The perception of needs for special care, in addition to the desire to provide appropriate incentives that will encourage the development of the child, in some cases, can cause the mother to leave their jobs, making them to dedicate exclusively to their children. [18] In general, they are unable to exercise activities out of home because of the time required

for childcare. Some women who were mothers and workers give up work for the inability to divide their time between the two activities. [15]

In this perspective, in order to meet the demands of care of the disabled child, and also due to the initial difficulty in dealing with the feelings and conflicts experienced, mothers feel unable to have the life they had before the arrival of the child, thus dedicating to the demands imposed by the situation experienced in the family and in his/her care. [19]

Based on the narratives, it becomes noticeable the annulment process that those women are placed to devote themselves to the care of their children, revealed from the affectivity and accountability, as evidenced among mothers of disabled children. On the other , we can identify a victimization process, in which the woman positions herself as self-reports as damaged in her life story, focusing on proactive care, seen not only as an act, but also as an attitude that covers more than a moment of attention, for it represents an attitude of occupation, concern, responsibility and continuous affective involvement with the other. [20]

Given this reality presented by the mothers in their speech, there is an immediate need to refer to a more focused care for themselves, especially through the context of caring for a disabled child who requires completion of their core, and must intertwine in the environment that permeates their life and the life of their child.

### Influence na conjugal and family life

It is noteworthy that, for some women, being a mother and caring for a disabled child becomes a task performed solitarily. There are few who can count on the help of the partner, highlighting the role culturally imposed on women in the family and the mother's burden regarding the care of her child.

One observes that the study collaborators had their conjugal bonds broken after the child's disability discovery, as the speeches below:

*Soon after we discovered Kailane was especial, my husband and I got separated, and it became even harder for me*

Kryslane.

*The most difficult moment for me was when I got separated from my ex-husband and had to take care of her all by myself.*

Isadora.

*With the separation, I suffered a lot and said: My God! Wanting it, or not, he was my support so that we would live together and raise our daughter. The biggest challenge of my life is to raise my daughter without her father*

Kryslane.

A conservative family environment, throughout history, puts ideological attention on the child, making the mother the essential character of the care at the expense of the father. Thus, many women accept to sacrifice themselves for their child to live, and live better, with her. [21] Given this situation, the mother assumes a role of caregiver within the family context, while the husband is responsible for the physical and financial support. [22]

Caring for families experiencing their living with a disabled child is essential to strengthen them in the face of adversity caused by the child's disability and to maintain the healthy family functioning and interactions. Given the process of adapting to the new situation created by the needs of a disabled child, they need to rethink their organizational structure and shape as a group, for the childcare may require the constant presence of one of the members, overloading them. [23]

One infers that those mothers, in addition to the physical burden of taking care of the children by themselves, they undergo a suffering of loss and loneliness of the person with whom they envisioned to build a family. Generally, the mother takes the most present role; however, it is important that

other family members, especially fathers, participate in consultations, so that the mother find greater support among family members, especially with regard to practices and guidelines. [16]

## Conclusions

The study sought to portray the meeting of women with the reality of being a mother of a disabled child, where they found, throughout the way, many challenges such as the fragility of self-care and social-affective relations, the resignation of academic and professional career and separation with the spouse.

One highlights the instability of assimilated roles in the life story of these women amid the dilemma of caring for themselves and the child with disabilities. They confronted their humanity and discovered weaknesses and limitations in dealing with the issues of her own lives and the responsibility to make correct choices concerning the life of the child.

One perceives that by giving up personal achievements to meet the childcare needs, women look forward to changing their reality. Thus, there is the resilience of those women who became mothers, and in the meantime, found the strength to deal with unwanted reality expressed in the expected child.

The emotionally unhealthy condition those women experience when they become mothers of children with disabilities is evident. However, one emphasizes the detachment and perseverance to stay with their children, providing the necessary care to maintain their well-being, often with a personal resignation.

It is noteworthy the need to support those women, as well as subsidies and support for those children to access the available treatments and inputs through the organization of health services and social and family support network. One suggests new approaches integrating the families of children with disabilities, where the professional-parent relations-

hip is a true partnership, with both working to meet the needs of children and families.

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