

Go to Fight! parents' experiences in caring for their disabled child

Ir à Luta! vivências dos pais nos cuidados do filho com deficiência

DOI:10.34117/bjdv7n12-771

Recebimento dos originais: 12/12/2021

Aceitação para publicação: 29/12/2021

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ABSTRACT

The objective was to understand the experience of parents in caring for children with disabilities. The Grounded Theory was adopted as a methodological framework, 9 parents of children and adults with intellectual or multiple disabilities were interviewed, between August/2015 and June/2016. The categories were obtained: Pre, peri, post-natal aspects, Posture assumed by the professional, Go to Fight! and Another world. It is, therefore, a parenting that is configured as these parents enter the Another world, which leads them to adjust their practices and beliefs about their child, about themselves and the universe of disability, sometimes under a perception of disability as a social disadvantage and incapacity, having as an intervening factor the Posture assumed by the professional, thus knowing these experiences from the GT allows: the improvement of care practices for these parents and their children, the planning of actions psychoeducational from a social perspective of disability in order to empower them and guide them about aspects of their children's development, enabling a look beyond the diagnosis and a more positive family adaptation.

Keywords: Grounded Theory, Parenting, People with disabilities.

RESUMO

Objetivou-se compreender a vivência de pais nos cuidados com filhos em condição de deficiência. Adotou-se como referencial metodológico a Teoria Fundamentada nos Dados, foram entrevistados 9 pais de crianças e adultos com deficiência intelectual ou múltipla, entre agosto/2015 e junho/2016, a partir de um roteiro semiestruturado. Obtiveram-se as categorias: Aspectos pré, peri, pós-natais, Postura assumida pelo profissional, Ir à Luta! e Outro mundo.

Trata-se de uma parentalidade que se configura na medida em que estes pais adentram no Outro mundo, que os leva a ajustarem suas práticas e crenças sobre seu filho, sobre si mesmos e o universo da deficiência, por vezes sob uma percepção da deficiência como desvantagem social e incapacidade, tendo como fator interveniente a Postura assumida pelo profissional, assim conhecer essas vivências a partir da TFD permite: o aprimoramento das práticas de assistência a esses pais e seus filhos, o planejamento de ações psicoeducativas a partir de uma perspectiva social da deficiência de modo a empoderá-los e orientá-los sobre aspectos do desenvolvimento de seus filhos, possibilitando um olhar para além do diagnóstico e uma adaptação familiar mais positiva.

Palavras-chave: Teoria Fundamentada, Relação Pais-Filhos, Pessoas com deficiência.

1 INTRODUCTION

The concept of parenting emerges in the 60s, from studies of Psychology and Psychoanalysis in reference to the psychic processes arising from the relationship of parents with their children, and from the subjective changes resulting from the desire to have a child (ZORNING, 2010).

Martins, Abreu and Figueiredo (2017) when studying this concept, they applied a semi-structured interview script with 15 parents, being a separate father and mother, in five different moments of the transition process to parenting (first days, 1st, 4th, 6th and 12th month of the child's life). The authors identified Being a father, being a mother: a process under construction in the interaction as the main category and highlighted the fact that parents initially did not feel prepared for the experience of parenting. They observed that for father figures, being a father is born with the child and at the moment of delivery, while for mothers, being a mother begins with pregnancy. Additionally, the data revealed the role of the parental gender variable, since the main care is still linked to the maternal figure, which contributed to the mother's greater burden.

In this phase of the family life cycle, the transformation of the couple into parents changes the relationships and routines established between the couple and between them and the extended family, regardless of the child's characteristics, whether with typical development or with disabilities. Dantas et al. (2019) in a meta-synthesis, they analyzed eight studies on the repercussions for the family of the birth of a child with multiple disabilities and identified three themes: disability and ideal parenting; the burden of care for parents of children with disabilities; and the (re)meanings and adaptations of the family.

The organization of data from this meta-synthesis revealed that the social restriction experienced by parents was a concept linked to ideal parenting and resulted from their attempt to protect themselves and their children from stigma and prejudice, from the embarrassment of

being observed, ridiculed. Thus, their actions in relation to their socialization and that of their children and the changes implemented in the family's routine were strongly influenced by the beliefs and behaviors of others about the child's disability (DANTAS et al., 2019).

Social prejudice was one of the sources of stress reported by 19 women, mothers of children diagnosed with cerebral palsy (CP), along with: birth of the child with CP, lack of information on the part of doctors, difficulties with the great demands of care and having to cancel their own lives to take care of their child. Religiosity and love, on the other hand, proved to be important for these mothers to continue taking care of their children, despite the challenges, fatigue and physical and emotional pain, the latter due to the stigma about disability (RIBEIRO et al., 2016).

Santos and Pereira-Martins (2016) identified the search for social support and religious practices as the most common coping strategies in parents of children with ID. In the case of mothers of children and young people with varying degrees of impairment caused by the diagnosis of CP, it was noticed that as the child grows, mothers have more coping strategies becoming safer in the exercise of parental care, even achieving resume some life plans (RIBEIRO et al., 2016).

Tomaz et al. (2017) when interviewing 15 mothers of people with moderate intellectual disabilities, they identified the mother as the main caregiver of this child, with a strict division of roles and the symbiosis between mother and child with ID proved to be a factor that strongly interfered in the relationship of this mother with the other children influencing the family dynamics. Baldini, Lima, Pina and Okido (2021) identified that older mothers receive less emotional and informational social support than younger ones, in a study with 36 mothers of children who need continuous and complex care. Thus, the authors highlighted the importance of offering emotional and psychological support to the mothers (BALDINI, et al., 2021; TOMAZ et al., 2017), and practical and social support, including income distribution and access to adequate services, since it is understood that the disabled child is if at risk (TOMAZ et al., 2017).

It is noticeable the massive participation of mothers in research on care for people with disabilities. Silva et al. (2019) discussed this female participation by the sexual division of labor, according to which the productive role with strong social value belongs to the man and the reproductive one to the woman. This pattern of division legitimizes the maternal figure as a full-time caregiver, distancing her from other social roles in addition to motherhood, which directly affects the quality of care of this child.

Silva and Fedosse (2018), on the other hand, analyzed the profile of 75 caregivers of people with ID, also considering their quality of life. It was identified that the care was exercised mostly in an informal way, by the mothers, full time, for prolonged periods (between ten and 20 years); these with low schooling and home occupation. Regarding quality of life, the domain with the highest average was social, in the case of women ($M = 79.6$; $SD = 10.20$) and physical for men ($M = 81.3$; $SD = 14.30$). The worst values were found in the environmental domain (Women: $M = 61.1$; $SD = 11.28$ / Men: $M = 59.6$ $SD = 11.86$) which involves topics such as security, financial resources, health and social care, transportation and opportunities to acquire information. The authors related this result to the insecurity and uncertainty experienced in relation to the child's development and Bulhões *et al.* (2020) corroborated this data.

It is understood that the difficulties faced by the family, either when defining the diagnosis, searching for information about the child's health status, in early childhood, or with the child already in adulthood having a routine of therapeutic care, can make the life of the main caregivers is even more tiring and exhausting, especially when it comes to less common syndromes (CERQUEIRA, ALVES, AGUIAR, 2016). Another aspect that needs to be emphasized is that the delay in the professionals' responses in relation to the diagnosis can delay necessary guidance and referrals to the family, increasing their doubts, thus favoring the emergence of escape behaviors and fanciful thoughts in view of the child's condition (RIBEIRO *et al.*, 2016), as the cure or improvement of symptoms, which generates even more frustration and pain for parents (DANTAS *et al.*, 2019).

The analysis of the process of closing the diagnosis until the guarantee of care and services for both child with ID in the study by Cerqueira, Alves and Aguiar (2016) and those with congenital Zika virus syndrome (ZVS) in the work of Bosaipo *et al.* (2021) revealed that the itineraries taken by the mothers of these children, demanded a lot of effort, dedication and abdication of their personal life. Among caregivers of children with disabilities, the practice of giving up work is frequent, since meeting children's demands were influenced by challenges of a different nature, such as geographic, economic and functional ones, with various comings and goings to health, education and health institutions and social assistance, some of them without any resolution.

When researching the experiences of conception, pregnancy and childbirth of 12 women, whose children were diagnosed with the ZVS, Carneiro and Fleischer (2018) identified in the report of these mothers, that the professionals provided little information about what happened with the baby, without hosting or supporting them. In most cases, information about the baby's condition came in the expulsion period, days after delivery and in two cases, after a

month of the baby's life; few were those who received the news of microcephaly during prenatal care. The authors also highlighted the excessive responsibility of women for conception, pregnancy, reproduction and care for this child with a severe condition of disability.

This unpreparedness of professionals when talking about the diagnosis with the family is evidenced by an inadequate or non-existent explanation to mothers about the development and care of their child (DANTAS *et al.*, 2019), negatively impacting the quality of care, since they often lack of guidance they learn through trial and error on how to act in a given situation with their child, without any direction (SILVA *et al.*, 2019).

In a study with a larger number of participants, Dias, Friche and Lemos (2019) identified that a quarter of the 871 users and companions of the services provided by the care network for people with disabilities in Minas Gerais, negatively evaluated the quality of care received in three of the four axes *Quality of Care Scale* (Access, Social Needs and Information Received). The data suggest that to increase the quality of care, it is necessary to: reduce the waiting time to receive care, offer services located close to where the user resides, facilitate access to consultations and improve communication with users.

Vieira and Favoreto (2016) identified three factors that can interfere with the effectiveness of health care for people with disabilities and genetic diseases in the Unified Health System (SUS), they are: the presence of stigmas, relationships marked by biomedical power and institutional violence. Often, the situations of violence narrated by the participants, were so naturalized in the provision of the service, that they were not identified as such by patients and family members. Faced with situations recognized as violent, they responded passively to maintain the possibilities of treatment, thus avoiding direct confrontation, evidencing the strength of biomedical power in disciplining the behavior of families.

Thus, the professional's approach can become a risk factor or protection for the child's development when communicating to the family about the child's disability. Because, like any child, a child with a disability needs his or her parents to be loving, giving them: availability, interaction and involvement (FRANCO, 2016). Therefore, the aim of this study was to understand the experience of parents in caring for children with disabilities. This article contributes to the planning of nursing interventions for such parents, especially in the initial phase of parents' adaptation to the diagnosis of their child's disability.

It is known that this adaptation phase is a complex phenomenon, as it implies the re-idealization of this child (LONDERO *et al.*, 2021), which is a process involving aspects of the child and the social environment, such as the stigma attributed to disability. In this sense, the

guiding question of this study is: How to characterize the experiences of parents of people with disabilities?

2 METHODS

The design adopted in this study was the qualitative approach based on the application of Grounded Theory (GT) to understand the phenomenon of parenting, from the perspective of codification by Strauss and Corbin (2008), which allows a greater understanding of the steps of the data analysis, favoring the improvement of the practices of professionals who work with this audience (MAIRINK, GRADIM, PANOBIANCO, 2021).

According to the GT, data collection and analysis must occur simultaneously, systematically, in a detailed, constant and spiral work, of collection, coding and analysis, through an inductive movement (in which codes, categories are developed and relationships between them based on the data) and deductive (testing them through comparisons between them and theirs with the data).

In this perspective, the collection did not start with a defined number of participants, but with a group, the parents of adults with disabilities (group I), and then, in the course of data analysis, with the aim of adding greater consistency categories, parents of children with disabilities (group II) were interviewed. The selection of these parents obeyed the following criteria: that their child had an intellectual or multiple disability and participated in a Program of interventions assisted by animals, in a public Higher Education Institution, headquartered in a capital of the northern region of Brazil, whose objective is to promote the biopsychosocial development of people with different types of disabilities. This Program is characterized, above all, by offering activities carried out with animals as co-therapists and / or motivators with the objective of assisting in the biopsychosocial development of young people and adults with disabilities.

A semi-structured interview script composed of two parts was applied: I - Sociodemographic data with eight closed questions and II - Specific questions consisting of three open questions, starting with the following question What does it mean for you to have a child with a disability? The insertion of new topics in the interview respected the rhythm, content and pauses in the speeches of the participants so that they were asked about two other aspects: the changes arising from the diagnosis / birth of the child (What has changed with the birth / diagnosis of a disability in your child?), and the future projections for you and your disabled child (What do you expect in the future for your child and for you?).

Initially, for data collection, contact was made with the Program's general coordination, which approved the execution of the research. Then, the parents whose children participated in the Program's activities and met the selection criteria were identified. It was agreed to identify them from P1 to P9, for parents and from F1 to F9, for their children, respectively, with a view to preserving their identity according to ethical precepts. During the collection, none of the participants decided to stop their participation. The interviews were conducted at the location chosen by the parents (in a room in the Program or in their homes). In general, the interviews lasted between 40' and 50'. It is noteworthy that the data collection took place between August 2015 and June 2016, reaching theoretical saturation for the relevant concepts with the nine interviewees. After each interview, its content was transcribed and analyzed manually.

This study respected the ethical aspects and legal implications of Resolution No. 466/2013 of the National Health Council of the Ministry of Health. Data collection started only with the authorization of the Research Ethics Committee of the Nucleus of Tropical Medicine of the Federal University of Pará (Opinion No. 1,125,916) and the signing of the Informed Consent Form (ICF) by those who accepted to participate in this study.

3 RESULTS AND DISCUSSION

In group I, composed of six caregivers, the average age was 53.66 years, $SD = 8.71$. The schooling of the group was concentrated in complete high school ($N = 3$). With regard to family income, the majority was concentrated in two categories, from one to two minimum wages and from two to three minimum wages (each with $N = 3$). Of the six participants, four had a spouse and two were without a partner. As for the occupation, two were engaged in some paid activity, four were housewives. Of this group, five were mothers and one, father. In relation to children with disabilities, in this group, three have ID and three have a diagnosis of CP associated with ID, placing them in the multiple disability category, the mean age of the children was $M = 28$ years with a standard deviation of $SD = 6.69$.

In group II composed exclusively of mothers ($N = 3$), the mean age was 41 years old, $SD = 9.53$. As for education, two of them had completed higher education, which also had a fixed job. As for family income, each one fell into a range, one to two minimum wages, two to three minimum wages and five to ten minimum wages, the first two were single and the one with the highest family income was married. Two of the children had CP associated with ID, classifying them in the multiple disability category, the average age of these children was $M = 9.66$ years, with $SD = 2.51$.

Of the nine participants, eight were mothers who acted as primary caregivers for their children with disabilities, six of whom were housewives. A similar result was discussed by Silva et al. (2019), Silva and Fedosse (2018) and Bosaipo et al. (2021), in which the main care, in its majority, was informal and was given full time, and for long periods of time, exercised by women, with low level of education and economically needy.

The microanalysis applied to the transcriptions resulted in several codes, which, when grouped, through an inductive analysis, initially generated 30 provisional categories. At the end of the codification process, four categories remained: Pre, peri, post-natal aspects, Posture assumed by the professional, Go to Fight! Parents' experiences in caring for their disabled child and Another world.

3.1 PRE, PERI, POSTNATAL ASPECTS

The aspects that preceded the birth of this child, such as the prenatal status of the mother and baby (healthy or not) and the conditions of the delivery (with or without complications) were themes present in the statements of most parents of both parents. groups to explain your child's disability. P2, when reporting complications during his wife's labor, blames the doctor for her daughter's cerebral palsy:

how do we call it? Is it incubator? It's an incubator because they put oxygen in it, it was intubated, so I saw it with the bandage, it was with a bandage, then I said "-why does she have this bandage?" she said "her arm was broken" broke in two parts, until today I have, I have the radiography, I have everything kept in the hospital and she spent about 25 days (interview held on 10/26/15 with P2, 55 years old, father of 26 years old, cerebral palsy, multiple disability).

In the speech of P8, for example, in addition to identifying changes in the child's development shortly after birth, indicators of the Posture assumed by the professional in contact with the parents were scored. Since P8, when asking doctors after childbirth, about whether their child has Down's syndrome or not, they answered: "Look, we have a little doubt" (anesthetist); "There is a great suspicion, but you have your eyes pulled, let's see" (neonatal pediatrician). During the P8 pregnancy, the doctors did not report anything about the baby's risk of having Down Syndrome.

3.2 POSTURE ASSUMED BY THE PROFESSIONAL

In many speeches, the professionals were mentioned as those who have the knowledge and information valid for this child. P6, for example, says that they (parents of a child with a disability) do not know anything, "because it is nonsense to say that we have a special child and

know everything, we know nothing. We exchange experience, but we don't know, right” (interview held on March 9th, 16, with P6, 68 years old, mother of F6, 35 years old, intellectual disability) demonstrating the superiority of biomedical knowledge to the detriment of his as mother. A knowledge as highlighted by Vieira and Favoreto (2016), whose values support the discourse of inefficiency, incapacity, of a problem that belongs to the person, reinforcing stigmas about him that can interfere in his care by the health team.

The doctors' failure to guide the family reflects the feeling of inability to deal with the different (CARNEIRO, FLEISCHER, 2018; VIEIRA, FAVORETO, 2016), since the suspicion of a disability leads to the need for specialists to define the diagnosis, explain and guide the care and stimulation practices. This feeling of incapacity can also afflict parents, preventing them from realizing that in many cares. Their children's needs are more related to the stage of their development (TOMAZ et al., 2017), than to the diagnosis and mainly to the parent-child relationship (FRANCO, 2016), i.e., that this, like any other child, it needs affection and availability, which in turn will depend on how the parents experienced their process of adaptation to the diagnosis (LONDERO et al., 2021).

Thus, the posture assumed by the professional in the face of the child's diagnosis was an intervening condition that guided the parents' actions, making it difficult or easier for them to value their knowledge regarding their child's characteristics, as well as seeing positive aspects and development possibilities in him, beyond the condition of disability (SILVA et al., 2019). In this sense, the attitude of the professionals when communicating the diagnosis, especially if they inform themselves clearly or not about the characteristics and prognosis, was configured as a risk factor or protection for the child's development.

Once guided by professionals who referred more to the disruptive characteristics of the diagnosis and having the typical development as the standard, some parents followed this perspective, often ignoring their child's development possibilities, feeling unable to take care of this child. This stance made it difficult for parents: the recognition of specific demands for transitions in the life cycle (the child's entry into school, early adolescence, etc.), which are common to any child / youth / adult and their self-perception as capable of taking care of your child with disabilities in a positive way and favoring their development.

According to Dias, Friche and Lemos (2019), the improvement in communication with users was an aspect highlighted as necessary to the services provided by the care network for people with disabilities in Minas Gerais. Hence the importance of the posture assumed by the professional in the process of adapting these parents to the condition of their child's disability. It is necessary to receive more welcome from the team and availability to clarify the doubts of

the parents and to undo their fears, strengthening their knowledge about their child (BULHÕES et al., 2020). This posture will contribute to the exercise of positive parenting, avoiding the appearance of fanciful thoughts about the child's disability condition, whether underestimating its severity or overestimating it (SANTOS, PEREIRA-MARTINS, 2016), to prevent this child from being exposed to the risk of rejection, abandonment or institutionalization, increasing the risk factors for its development.

3.3 GO TO THE FIGHT! PARENTS' EXPERIENCES IN CARING FOR THEIR DISABLED CHILD

The phenomenon started with the parents' report regarding their actions in caring for the disabled child, during and after the diagnosis was defined, they were: resorting to care in general - clinical or outpatient; resort to home treatments, data also present in the studies by Cerqueira *et al.* (2016) and Santos and Pereira-Martins (2016) and also, allowing oneself to learn from the child; fight for the rights of the child and talk to family members and/or other mothers of people with disabilities.

These actions and strategies of the parents occurred in the sense of seeking a vast amount and diversity of treatments and activities for the children, in order to mitigate possible delays resulting from the diagnosis, as in the report of P7 on the care and rehabilitation institutions that the daughter has attended until the time of the interview:

From the neuro, I looked, she did it at the ERU, there at AlcindoCacela, right, and she did it at Fisiomed. Always doing it, then I met Sarah, who was not here yet, I went to Macapá as I had a relative, I went to Sarah. Then, I was transferred here, as I had here. I always looked, everything that was within my reach, she did hippotherapy in Castanhal, two years, then it ended Castanhal did here, two more years. There he went to Saber ... (interview held on 04-14-16, with P7, 50 years old, mother of F7, 12 years old, cerebral palsy, multiple disability).

It is observed that some parents like P2 report difficulties in reconciling the care routine of their children with their life routine when considering that “people's lives do not become normal, with a child like this it is difficult!”. However, other parents, such as P8, highlighted the ability to learn about this care when saying that “we learn to push a wheelchair, which for me was new, we learn to take care of the child, in certain situations, especially in the seizure, that I still get nervous”(interview held on 01-06-16, with P9, 31 years old, mother of F9, 10 years old, cerebral palsy, multiple disability). P3, emphasizing his capacity for development in the face of adversity caused by his son's disability, says: “Even his father said that I was unable

to take care of the boy (...) He thought I had no experience, but I, I learn” (interview held on 12/14-15 with P3, 51 years old, mother of F3, 31 years old, cerebral palsy, multiple disability).

Another common strategy in this experience of the parents was to make adjustments in their routine of life, which included demands: family, study, work and leisure (in extreme cases, leaving the job or study, by one of the parents who assumed the role of primary caregiver, as it is a group with low purchasing power) (SILVA et al., 2019; SILVA, FEDOSSE, 2018). These adjustments were necessary both at the beginning of the phenomenon with the insertion of the child in the routine of care, and over time, at the time of the interviews, both for children who are adults and for those who are children. P3, for example, like other mothers, had to quit their job to take care of their child: “I quit everything, I have a profession, I took a technical nursing course when I was very young. There I got pregnant, there was a special boy and I had to drop everything, take care (...)” (interview held on 12-14-15 with P3, 51 years old, mother of F3, 31 years old, cerebral palsy, multiple disability).

This burden of the mother as the primary caregiver was evidenced in the study by Martins et al. (2017) in women who had just become mothers of babies with typical development, as well as in studies with parents of children with disabilities (RIBEIRO et al., 2016; TOMAZ et al., 2017; BALDINI et al., 2021; SILVA et al., 2019; SILVA, FEDOSSE, 2018). Having a child in a condition of disability imposes on women not only the incorporation of a new social role, but also specific care practices, which will occur throughout the life of that child, often resulting in the exclusion of other roles, as in most cases there is no sharing of this care with the partner (CARNEIRO, FLEISCHER, 2018).

The experience of becoming this mother will therefore require coming and going to health, education and social assistance institutions (CERQUEIRA et al., 2016), greater financial demand and adjustments in family dynamics (SILVA et al., 2019), plus the experience of prejudice with the child. Thus, these changes added to the social perception of the person in a condition of disability as unable to assume their life with autonomy (RIBEIRO et al., 2016; SILVA et al., 2019) are aspects that need to be considered by professionals in general and more specifically by those who deal directly with this group, and were concepts identified in the speeches and organized in the category Another world (in vivo code) discussed below.

3.4 ANOTHER WORLD

P8 described the new routine with the child as Another world:

When I'm with the hippotherapy people, there are other children too, there are few, few children with down syndrome, but I feel happy to be part of this world, understand?! For being there. Every time I am there, when I see everyone, in our social gatherings, in the actions that take place, I am moved, very moved, because I already see myself there, in that story, being part of that. Today I don't know if my life would have the same meaning, do you understand? (interview carried out on 18-05-16 with P8, 42 years old, mother of F8, 07 years old, Down syndrome).

When adding care to the disabled child and other practices necessary to maintain them in their routine, it implies several changes in the family and the insertion of caregivers in new contexts. One of the most frequent changes in the speech of these parents was in the family's finances, which occurred either due to the increase in expenses due to rehabilitation treatments and/or the departure of a parent from work to exercise the child's care. This change resulted in a drop in the family income of most of these parents, revealing the economic vulnerability to which these families are exposed (DANTAS et al., 2019; SILVA, FEDOSSE, 2018; DIAS, FRICHE, LEMOS, 2019).

With regard to the consequences for the health of the primary caregiver, the concepts encompassed both physical and social aspects (DANTAS et al., 2019). As can be seen in some statements: "(...) even the mothers who are there at UFRA, right, at IOMPA, so tired, so exhausted with everything, there are mothers who do not sleep well, I have already passed for this situation (...) "(interview held on 08-24-15, with P1, 41 years old, F1 mother of 20 years, intellectual disability); "I have a broken vein here in my arm (shows the vein in my right arm) then look, it's still from the time I held it (...)" (interview held on 10-26-15 with P2, 55 years old, father of 26 years old, cerebral palsy, multiple disability); "(...) I never went to a party, but I always liked to dance, but my social life was zero, zero, zero, zero, zero, as it is today, right?!" (interview held on 03-09-16 with P6, 68 years old, mother of F6, 35 years old, with intellectual disability).

These findings are consistent with the data by Silva and Fedosse (2018) who, when researching the quality of life of caregivers of people with DI, identified the lowest score in the assessment of the environmental domain, for men and women, precisely what involves health and social care, in addition to financial resources.

On the other hand, these parents reported receiving support (SANTOS, PEREIRA-MARTINS, 2016) in the adjustments in their routine of life and/or in the type of treatment offered to the child, having as a source, in addition to family members, people outside the family circle, as well as other parents of people with disabilities and professionals of health. P9, who lives in a city in the interior of the state, reported the friendship between the mothers through

mutual help and a commuting routine from where they live, to the capital where their children are treated.

There was also the support offered by family members due to the disruption of the marital relationship³. P6 emphasizes this family support as fundamental for the well-being of their children “Look, I have a brother who is not a brother, he is my father, he is the father of my children (...) he helped me to raise my children, because they didn't even give me a pension, ever ” (interview held on 03-09-16 with P6, 68 years old, F6 father, 35 years old, intellectual disability).

Another aspect that permeated the entry into this Another world was the experience of prejudice by the child and with the child who referred to situations of discrimination, experienced by both the parents and the child, witnessed or not by them. At times, the prejudice came from family members, at other times from strangers. Similar reports were identified by Dantas et al. (2019), and the result of this was isolation and social restriction in order to protect themselves and their children from the embarrassment and humiliation caused by prejudice.

P3 reported the prejudice of strangers and that of her husband, attributing guilt and disqualifying her ability to care for her disabled child:

At first, they said I had taken medicine to abort him (pause), when he was a little boy (...) Then I would pass him, he played, people would say: 'Do you know what this is? You went to take medicine to abort him' (interview held on 12/14-15 with P3, 51 years old, mother of F3, 31 years old, cerebral palsy, multiple disability).

According to P9, prejudice is constant: “Every day there was a situation of prejudice” (interview conducted on 01-06-16, with P9, 31 years old, mother of F9, 10 years old, cerebral palsy, multiple disability). Likewise P1,

There is still discrimination, people say it is over, but I think it is not over yet, there is still this taboo, this prejudice in relation to people with disabilities, and we know that where we go we will face a problem, right? (emphasis added, interview carried out on 08-24-15, with P1, 41 years old, F1 mother of 20 years old, intellectual disability).

P9 when reporting prejudices that the daughter and she suffered argues about the need for society to "understand the disability of others". "What would the world be without them?" These reflections demand a change in attitude towards the person with a disability, that is, looking at him mainly as a person, that is, someone with feelings, tastes, skills and difficulties, able to act in the environment, in his own way, with support and opportunity. contributing to it

and the people around it. These are beliefs and attitudes no longer centered on disability, but on diversity and acceptance of differences.

This exposure of people with disabilities and their families to social perception, of the disabled as incapable and dependent, affects them to the extent that they weaken parental relationships with this child in order to direct care practices based on the model of social disadvantage and consequently influence the relationship, between the couple, with the other children and between the siblings (DANTAS *et al.*, 2019; SILVA *et al.*, 2019). Thus, these parents become dehumanized, since they suffer from the same social stigma as their children, the struggle for the child is mixed with a struggle for themselves, for their humanity, as P9 says, “And what would the world be without us to take care of them?”.

4 FINAL CONSIDERATIONS

As the data was collected, the dimensions of this struggle became even more evident. Go to the Fight! to obtain explanations, guidelines, definition of diagnosis from contact with specialists and in view of their proposal regarding the appropriate treatments for the child with disabilities, fight for the rights of the child, their schooling and family and social inclusion. Going to the Fight! implies a care routine that often proved to be suffocating to the main caregivers, making them prioritize the exercise of parenting and neglecting, for some time, other roles.

From the analysis of the actions of these parents in a contextualized way, that is, considering not only the child's diagnosis, their care demands and the support received (micro conditions), but also these parents' beliefs about: being a father/mother; having a child with a disability and that of the professionals who care for them (macro conditions) it was possible to understand the experiences of this audience. A parenting that takes place as these parents enter Another world, which leads them to adjust practices and beliefs about their child, about themselves and the universe of disability, sometimes under the perception of disability as social disadvantage and disability.

In this sense, the Posture assumed by the professional as an intervening condition in the phenomenon Go to Fight! it shows itself capable of both enabling a positive adaptation of the parents, as well as a negative one in the experience of caring for their child in a condition of disability. Thus, professionals who work directly with these parents and / or their children should be advised about the variables that make up this parenting so that they promote practices favorable to family adaptation.

The Go to the Fight! it then refers to both the care practices common to the fact of being a father and the changes in the family routine due to the arrival of a new member, as well as adding those specific actions of the child's disability condition, even extrapolating to other contexts in a different way. to guarantee not only the child's inclusion in the family, but also in school and society.

Among the operational difficulties found to carry out this study, there was: the time interval for the execution of this proposal, because when considering the systematization of GT and the volume of data that it allows to analyze, it is observed that the variable time, as well as good management is important to ensure the refinement of concepts and categories. The constant collection and analysis of the data implies the availability of a population, parents of adults with disabilities, who frequently organize their routine in the domestic space, which makes it difficult for the researcher to access it.

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