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From dream to reality: a disabled child is born

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Abstract*:* This work aims to outline the repercussions of the news of a child's disability on the family and the couple's life, how they deal with this new reality, how they reorganize themselves to receive this child, and what support network they can build. It's a descriptive, exploratory, qualitative approach study. Semi-structured interviews were carried out with nine mothers and eight fathers of children aged up to two years. The data were analyzed using content analysis in thematic mode. The results point out the pregnancy and its expectations, show how the parents organized themselves for the arrival of the baby. Despite their different expectations, they started reorganizing their routines; the news of the son's disability, which brings together different feelings of helplessness, insecurity and doubts about the future; the arrival of the baby which, after denial, comes with a series of worries, adaptations and fear; how they organized themselves for care as many parents had to choose who would stop working to take care of the child. The adaptations made by the family were structured to assist the disabled child, seeking comfort, and a good life. Having a child with a disability requires a lot of dedication from parents, and families need support from health services so that they can talk about the difficulties experienced and possible paths to a better quality of life for their children.

Keywords: pregnancy feelings, disabled child, impact of the child's disability on the couple.

Do sonho à realidade: o nascimento de um filho com deficiência

Resumo: Este trabalho visa conhecer as repercussões sobre a notícia de deficiência de um filho na família e na vida do casal, como lidam com esta nova realidade, como se reorganizam para receber esta criança e qual a rede de apoio que conseguem construir para isso. Estudo descritivo, com caráter exploratório e abordagem qualitativa. Foram realizadas entrevistas semiestruturadas com nove mães e oito pais de crianças de até dois anos. Os dados foram analisados a partir da análise de conteúdo na modalidade temática. Os resultados apontam a gravidez e suas expectativas, mostram como os pais se organizaram para a chegada do bebê que, apesar de distintas, começaram a reorganizar suas rotinas; a notícia da deficiência do filho, que reúne sentimentos diferentes de desamparo, insegurança e dúvidas quanto ao futuro; a chegada do bebê que, após a negação vem como uma série de preocupações, adaptações e medo; como se organizaram para o cuidado já que muitos pais tiveram que optar por quem iria deixar de trabalhar para cuidar da criança. As adaptações realizadas pela família se estruturaram de modo a assistir a criança com deficiência, buscando conforto e bem viver. Ter um filho com deficiência exige dos pais muita dedicação e as famílias necessitam de acolhimento dos serviços de saúde de forma a que possam conversar sobre as dificuldades vivenciadas e os caminhos possíveis para uma melhor qualidade de vida de seus filhos.

Palavras-chave: gestação, filho deficiente, impacto da deficiência do filho no casal.

Introduction

The news of a pregnancy presents parents and their families with a unique moment, filled with many emotions and feelings. The birth of a child triggers a new transition in the family life cycle, where the couple dyad broadens to a couple plus child triad, the couple's affection revolution is followed by a redistribution of roles, functions, and identifying images. These occur in three levels: in the privacy of the couple, in the relations between the couple and their original families and the relations with their most significant contexts (professional, friendships, social support networks etc.) (Costa, 2011).

A family organization involves planning routines, physical space, and purchasing goods that may facilitate caring for a newborn. This is also a moment for idealization, as well as emotional, behavioral, social, and economic changes that characterize the arrival of a new member for a family. However, each family's reality is unique, and families experience different life contexts regarding pregnancy. Some plan pregnancy, while others do not; some have more financial resources and social support than others. Despite the various differences between them, this period is known as a "hormonal, physical and psychological earthquake" because it poses enormous challenges and uncertainties involving the unknown and causing insecurity regarding the whole process of pregnancy and childbirth (Caron & Lopes, 2014).

Each month, with the sensations experienced as the fetus grows, medical exams and guidance are carried out, and the imaginary baby starts to reflect in the real baby and form a child identity in the couple. The heartbeats, the revelation of the baby's approximate size and weight, the baby's gender reveal, the baby's formation are situations that bring the family's dreams and expectations closer to reality. This imagination is ruptured when a family hears the news that their child will present some kind of disablement while it is still in the mother's womb or right when it is born (Costa, 2011). When a child is born disabled, this fact may trigger reactive behaviors in the family. There are parents who can realistically deal with the problems to faced due to their child's having some kind of disablement, in the same way they deal with other crises in their lives (Marques, 2019).

The impact caused by the news of disablement is characterized by a mixture of feelings in the couple and their families such as love and hate, joy and suffering, acceptance and rejection, euphoria and depression, as well as feelings of anguish, fear, guilt, and shame (Amaral, 1995). This is a distressing experience that deeply alters internal and objective relationships of all persons, and it redefines familial and social roles of each member for a long period of time (Brito & Dessen, 1999).

Many parents deny the existence of disablement in one of their children because the cultural stereotype of a child is one who is healthy and problem-free. They place too many expectations on their children and hope that they either reach or surpass their own endeavors, and they hope that they can go further in life regarding their personal and professional development (Marques, 2019).

Considering how important it is to investigate this type of family, who usually feels lost and helpless, this work aims to outline the repercussions of the news of a child's disablement for the family. It explores how they deal with their own expectations and this new reality, how they reorganize themselves to welcome this child, and what support network they can build.

Method

This study was carried out at a Parents and Friends of Disabled Children’s Association (APAE) of a city located in the metropolitan area of Rio Grande do Sul. Nine parents (fathers and mothers) of babies who are seen every week at the Early Stimulation Sector of this institution participated in this study. The inclusion criteria were families of patients who were being seen due to the child’s disablement specialty until October 2018, aged up to two years, and children who already had a disablement diagnosis. The families of patients who had been undergoing investigation, that is, those without a finalized diagnosis of the disability, as well as patients aged over two years were excluded from this study.

The families who met the inclusion criteria were contacted by telephone and invited to participate in this study. After agreeing and signing the Free and Informed Consent Form, the interviews were scheduled at a time and place chosen by the interviewees. The interviews presented guiding questions specifically made for this purpose and lasted for about one hour. Fathers and mothers were interviewed separately.

The data were analyzed as per the Content Analysis Technique proposed by Minayo (2016). According to this perspective, the theoretical framework is represented by the (theoretical) concepts that are related to the units of meaning (taken from the research subjects’ accounts). The latter can be divided into recording units and context units. Recording units are sentences or prayers that gravitate around the messages that the subjects give us during data collection. They are obtained from decoding the message. The context units are the broadest reference, that is, the context that is part of the message

(Minayo, 2001). Data analysis is a reality organization procedure to investigate facts and the relationships between them.

According to Resolution no. 466/2012 of the Ministry of Health, data collection only started after this study was approved by the Research and Ethics Committee by opinion no. 3.291.134. Besides, this study guarantees participant anonymity, using fictitious names that had been suggested by the interviewees for the presentation of their statements.

Results and Discussion

The results discussed herein were organized according to three topics: pregnancy and its expectations; the child disablement news: the investigation and diagnosis period; the impact of the arrival of the child with disabled child; how families rearrange after this news. This discussion was carried out after comparing this results of this study and those of existing studies in this field in order to achieve this study objectives.

Pregnancy and its expectations

To understand the arrival of a child in the life of a couple and a family, you must be aware of what plans and routines existed before the decision or the announcement of a pregnancy. Finding out that one is pregnant triggers intense, varied, and ambivalent feelings that may unleash subconscious content of mothers and fathers (Brazelton & Cramer, 2002); the life of the couple may go through transformations in the imaginary realm and the real social system realms: the couple's relationship, familial relationship, friendship relationships, and others.

The arrival of a disabled child generates tension in the family's system and crises affecting the family dynamics emerge. The family sees itself as powerless and unprepared to deal with the new reality that is about to arrive. Expectations are shattered regarding the child about to be born, while the newborn's care needs tend to increase. The baby's parents are emotionally overloaded; there is disappointment, fear, and despair after the diagnosis is learned (Sá & Rabinovich, 2006).

This moment gathers emotions, feelings, and sensations reflected in romanticized and/or rational visions of the projection of an unknown future that is coming closer to the real after the expectations raised by the couple. The parents and their families start to reorganize their lives structurally; they cherish dreams and idealize a child according to characteristics that already exist in their family or are desirable in a child. Every pregnancy awakens a new world that, whether consciously or unconsciously, emerges from the news of the arrival of a new life: the physical and financial structure, managing time, emotions, plans for and with the child in formation, as well as other expectations related to existing different realities (Missonnier & Solis-Ponton, 2004).

The accounts below exemplify what it was like for the interviewees to learn about their pregnancy and how the couple rearranged to wait for the arrival of their baby. Many couples had to reformulate the plans they had before the pregnancy news. Yet, most of them said that everything worked out well.

> Before we had our daughter things were easy. My husband would be at his place, I'd be at mine. Let's date… OK, let's have a child, then… right? But we didn't decide whether we'd live together or not. Our daughter came, and it has been seven months since we live together at our home. As soon as she was born, we bought our home, but it still needed some renovation, you know? She was still a newborn. How would I go there? No we can live there, the three of us, you know… (laughs). I tell him we'd taken too many changes because first the two of them live, and then someone else comes. The three of us did not come at the same time, but everything is working out fine. (Alana, 38 years old, 1st pregnancy)

> (…) we were doing well. Both of us were working, we'd planned vacations together. It was the first year when we managed to take vacations together, which was February. (…) We'd planned vacations to renew our apartment, painting their room blue, take care of everything… And then, I did an exam and learned I was pregnant. I'd been taking medicine, but I think I missed out. We were so happy. We were scared, but happy. (Yasmin, 26 years, 3rd pregnancy)

The realities of the interviewed couples were different. The couples who had prepared to have child informed that their routines started to be either transformed and/or adapted to the arrival of a baby since pregnancy had been planned. They planned how they would organize themselves financially and logistically. In the case of those who did not plan pregnancy and were surprised by the news, they had to take some time to accept and absorb this news prior to organizing their families. They knew that everything would change after that moment as it shows in the parents' accounts.

> (…) she did a pregnancy test to clear her conscience, and then she called me saying that she'd been three months pregnant… It's two!" Wow… I started laughing, she almost

> went crazy (laughs) she did not believe it. That was not in our plans, it something out of the blue. Can you imagine three little ones!? We were a couple who was not used to having kids at home. She was 16 years old… Oh my God! What about construction work? What now? There is no space to build another room! We were troubled… (laughs) I had to change my whole room and place two cradles in it, and now we've lost our living room, and I have to make a room where the living room is! We had a very calm pregnancy… (Pedro, 45 years old, 4th child)

> (…) It had been two years since we wanted to have kids… Our expectation was the best possible, you know? Because a child was what we wanted, it was something planned. It had been two years since we were struggling to have a child, we had the best expectations… "Will it be a boy? Will it be a girl?" "If it is a boy, he'll play soccer," "if it is a girl, and so and so…" All the best expectations in the world for a child. What you are going to bring… clothes, if you will paint its room, if you will paint it blue or pink. (Marcos, 36 years old, 1st child)

As highlighted by the above accounts, after the impact of the pregnancy news, comes the reflection on the arrival of the baby. Whether it was planned or not, a mixture of feelings due to the several changes caused by the pregnancy comes to the life of the couple and their family. Besides the necessary structural organization, the expectations regarding the baby emerge.

In this representational parents' world, not only are the baby interaction experiences included, but also their fantasies, hopes, fears, dreams, memories of their own childhood, parent models and expectations for their future baby. Thus, the child is represented by present and past elements at the same time (Stern, 1997). A both unknown and scary stage of constant learning begins, as the interaction between the couple changes, and the reconstruction of their identities starts to exist (Oliveira, Galvão & Caires, 2020).

As early as during the prenatal period, the parents build a notion of their baby's individuality, by acknowledging some of its behaviors and temper characteristics. Since the early stages of the pregnancy, they establish a customary moment of interaction with their fetus via information such as the baby's sex and how it moves in its mother's womb, remarks that determine the structure of a precocious interaction pattern that tends to continue after birth. Knowing the baby before it is born, being with it, thinking about it, imagining its characteristics leads to implications to the construction of the baby's representation, maternity, and the further relationships between parents and the child (Borsa, 2007).

The couple starts to project how the baby will be and how life will be after its arrival. The expectations on this imaginary child that every mother and father build to themselves involve characteristics such as sex, name, how it moves in the womb and the psychological characteristics that will be attributed to him. The confrontation of this imaginary baby and the real one occurs after birth, but with the obstetric ultrasound, some concrete aspects can already be made known during gestation. These data can both stimulate fantasies as well as anticipate some frustrations (Szejer & Stewart, 1997; Thomas, 2016).

All interviewed women had prenatal examination, a moment that precedes the baby's arrival. They did tests and monitored the fetus's development. This is a moment of discoveries and even greater projections where revelations start to lead the couple and their family to an encounter between their dream and what is concrete, the present reality. With the help of imaging tests, the imaginary baby starts to become real; the size dimension, the sex reveal; the sensation of feeling a baby that is growing and starts to move in its mother's womb as featured in the reports below.

> I had my prenatal examinations. Thank God I did not have any complications. (I did) all tests, all ultrasound tests. It was a natural birth, that wonderful little pain… that almost drove me crazy… In my first child (pregnancy), I worked and made a point of paying for health insurance. We had all the assistance, and I had a C-section, but not with her… I was not working, and I wanted to go through the whole normal birth process. I do not want to do it ever again… (Cristina, 44 years old, 2nd pregnancy)

> (…) everything came out well in the exams, translucence, cardio, everything came out perfect. I remember I told my

> husband that it was a relief because no parente wants a special child. I remember he focused a lot on that. But I remember that, as a teacher, we see special children at school often, and let's be honest, no parent wants a child who will be discriminated against, sooner or later. (Alana, 38 years, 1st pregnancy)

There is a big difference between knowing about the existence of a life growing in a mother's womb and the first baby's movements. What was so different starts to be felt by the parents in a concrete way, and the bond between them and their baby begins to come closer. Each week of the pregnancy period is linked with a mixture of anxiety, expectations, and unique sensations, reflected in each family member according to their own vision and history. Along with the baby's needs, other identities and responsibilities are formed: a daughter becomes a mother, a son becomes a father, and the parents become grandparents (Borsa, 2007).

At birth, or in the moments subsequent to it, when a family has their real son before them, and the news that it has some disablement, among several confrontations comes the need of understanding who this child is, abandoning the idealized child, the intention of loving the child that was grown, adding a new affection bond.

This family, who had idealized a healthy child until the moment of diagnosis, is faced with their child disease. In that moment, various questions emerge as to why that happened; oftentimes, feelings of guilt, rejection, denial, or despair emerge among parents. This ends up causing changes in the couple's relationship and its structure. The diagnosis leads to grief for their idealized child (Milbrath et al., 2009; Thuy & Berry, 2013). Despite having had the prenatal examinations, the child's disease was not diagnosed before birth, which caused unexpected distress and tension to the couple and their whole families. Crisis moments occur because their expectations for an idealized child were shattered. The child's care needs are more intense, causing an emotional overload for the parents (Sá & Rabinovich, 2006).

The news of child's disablement: a period of investigation and diagnosis

When a child is born, the family experiences a transition from imaginary to real, and everything that was in the expectations realm is transported to concreteness. Moments before birth, parents anxiously wait that the child is developed according to what had already been read, heard, and expected about their baby. During the whole gestational period, the mother's diet requirements are explained: the breastfeeding stage, what to do when the baby cries, the badly slept nights, as well as so many other questions raised during gestation. No one is born knowing how to be a mother or a father, and that is part of a construction process linked to a family's various experiences (Sá & Rabinovich, 2006).

The parents who prepare for a reality projected on expectations and dreams during pregnancy, now, after their child is born, are confronted with a diagnosis that is too complex to understand, and they are filled with anguish. This makes adaptation and acceptance harder, which also occurs with their action in organizations that meet the newborn's demands, from building an affection bond to the child's direct care (Sá & Rabinovich, 2006).

The moment of birth is characterized by shattering imaginary projections. The diagnostic hypothesis that the baby has some kind of disablement comes with it. That is when several things go through the mothers' and fathers' minds. Besides fear and anguish, they must organize themselves to manage care for their newborn. This shall be very intense due to the child's disease, as the impact of the news on the child's disablement is oftentimes overwhelming (Sales, 2017).

> In the pre-labor room, in the first moment I saw her, I already knew she was different. She had these features on her face that, although I am not a specialist and there are no specialists in my family, those are things you hear about here and there and you assimilate them. I looked at that face and said, "She has Down." The pediatrician didn't come to talk to me, no one would talk to me. I thought, "Why are they preparing her to bring to me?" I started crying my eyes out… And then, the nurse asked me, "What happened, mom?" "My baby has Down, doesn't she?" And then she looked at me and said, "I think so, but someone is going to talk to you," and in the meantime, it seemed as if it was days, it might have been minutes, but that moment never came. And then her father saw me crying, and then the mentioned that he thought I was rejecting the baby, but that

> wasn't it. That never happened. I thought, "I'm not going to live forever, who is going to take care of my baby?" This is due to lack of knowledge, you know? We don't know what the syndrome is. (Ana Paula, 44 years old, 3rd pregnancy)

During pregnancy, at birth or in the first years of a child's life, its parents learn that their child is disabled. This reality mixes different feelings, as presented below.

> …we don't think it will be with us, right. In fact, we make a thousand plans and soon after that, it's like, "No, you can't do any of that." You have to start from scratch and see everything will be different! In fact, we must adapt our whole life for our baby. Everything is different! As mothers, when our baby is in the womb, we make a thousand plans. He'll be like this and that, he'll study one thing or another, and when we receive the diagnosis that our child is disabled, we feel so lost. (Bruna, 23 years old, 1st pregnancy)

The news about the child's disablement is given in different ways. This brings significative influence on the family's structure, who needs to meet their real son, a different child than what was expected in their imagination. They are daily challenges that must be faced by a family wishing that their child can have enough quality of life and calmness so that they can rearrange.

> (…) I followed the pediatrician, and they washed my little girl. He did some tests during her first bath. I noticed he kept on looking and looking… And I was like, "There must be something there… Something must be wrong. Her tongue is too stuck out. Right after that, he called me, and we had a talk in the room. He thought I was going to cry, who knows what happens to other people, you know? But I tried it like that… I'm a very calm guy, you know… I tried to keep myself cool at that moment. (João, 39 years old, 1st daughter)

This is a very delicate moment. Each person reacts in a certain way, according to their perceptions, their life history, maturity, and child idealization. When a newborn presents biological changes or in their behavior, their family experiences stress and anxiety. After the post-birth assessment, the investigation moment triggers the emergence of a hypothetical realm in the family where there is a cure to the changes that had been discovered. This period, which goes from the start of the assessments to the diagnosis definition, presents various feelings that make parents wish that their children are really the one who they had dreamed of so much, and they often deny reality and the final diagnosis. They experience contradictory doubts and feelings that may either help or hinder restoring the family's balance. In some cases, the family gets sick along with the child. Therefore, couples need time and follow-up to understand and accept their new situation. In case this balance is not achieved, the family structure shall remain affected and sick (Sá & Rabinovich, 2006).

Disabled children need full care from their parents; for this reason, the impact on their lives is enormous because it reflects on their time to provide necessary care while reorganizing their family and each parent's identity (Lunardi, Círico & Coldebella, 2011). From the hypothesis to the disablement diagnosis confirmation, one of the first parents' reactions is denial, as stated in the accounts below:

> The first thing I thought was, let's do a validation test. I'd always hear that. Before going to Physical Education school, I worked at a hospital, and we'd always talk about how we always need a second opinion. We should never go with the first opinion. I've seen doctors saying that things are a certain way but not another… (Marcos, 36 years old, 1st daughter)
>
> (…) and then, I started noticing that there was something different about my son. I spoke to his father, and he said I was making up a disease. He said, "You're making this up. He doesn't have anything. He's a normal kid. He's just angry like me." I said, "he's too young to be so angry or irritated." (Bruna, 23 years old, 1st pregnancy)

Idealization is the worst enemy of a possible happiness. People usually live idealized lives that are not actually experienced but presented to the public. Idealization does not help people acknowledge the facts of their lives and act upon them. Discontent aggravates suffering and our affection towards those who invent what the other person is and what we wish they were, and it prevents us from being in the presence of the real person (Aerts & Ganzo, 2009). This happens with the birth of a child and the expectations that we build around it. When a family receives a disabled child’s diagnosis, the families who idealized their child fall ill when they notice that their child is not like the one that only existed in an ideal world. This ends up preventing the family from loving who they exist (Aerts & Ganzo, 2012).

The feeling of fear of the unknown caused by the diagnosis and the uncertainties that may come from it present the family with much despair: how to love or project themselves as parents to an unknown child? The lack of support linked to the anguish and fear makes this moment even more confusing and sad as described in the account below:

> (…) after my echo, when my doctor said, “the translucency is really altered. There is a chance for the three syndromes. It might be born with one, two, three or none. It could be a heart condition,” and then I asked, “What am I going to do?” He replied, “You know you can have an abortion, don’t you?” I didn’t know what I was going to do, so I talked to my husband, and he said, “She is the fruit of our love. I know it’s your body, think about it, but regardless of how she comes, she’s a piece of you.” I decided I wasn’t going to have an abortion. If it comes out spontaneously, it’s in God’s hands… I got a doctor’s referral, the doctor saw all my exams and asked who told me to have this exam done, and I replied, “No one” because there was no doctor. he pulled all exams on me and said, “Unfortunately, I won’t do your prenatal testing.” I cried so hard in front of that man. I need help, I need support in my pregnancy, and then he said, “You have a high-risk pregnancy, you must have Fetal Medicine follow-up.” In this paper that he gave me, it

> said that my daughter had everything, but she wasn't blind. I thought, "how can they maintain that with the baby still inside me?" (Fernanda, 43 years old, 3rd pregnancy)

The hopeless parents experience, as described in the account above, could have been minimized it more adequate methods had been utilized to educate parents on their child's disablement diagnosis; that hopelessness could have also been minimized if health professionals had acted in a more humanized, welcoming way. The absence of these conditions may increase parents' difficulties in facing their new situation, given how decisive informing a diagnosis is, which marks the beginning of a new process of adaptation for all family's life (Guiller, Dupas & Pettengill, 2007). One must welcome and guide parents and families on the situation that they are facing so that they can feel more prepared and supported. The way they take care and welcome the child is key to their development. A child must be seen beyond its limitations, but especially in its potentialities (Oliveira, Galvão & Caires, 2020).

Information on the child's disablement, how compromising it is, its prognosis and the child's potentialities frequently reach parents. It is filled with prejudice, discrimination, and misunderstandings. The diagnosis moment is delicate. It is seen as a sentence that may change a child's "status," and it draws a dividing line between "normal" and "abnormal"/disabled. This word presents everything that is related to inadequacy, the impossibility of accomplishment, and it destroys the dreams and hopes parents invested in a child. Facing the certainty of a child with disablement, parents feel that they generated an unknown child and start wandering around, seeking information about the future of that child. Who is this child? Questioning, guilt, indignation, denial, depression, and grief are part of this conflicting moment (Sá & Rabinovich, 2006).

However, if a diagnosis generates internal conflict in each parent and between them, it also fosters resilience and courage to be able to face situations yet to come and the life demands of having a disabled child (Braga et al., 2011). The way parents deal with their newborn happens, the parallel conversations among the team, all the declarations and even lack of clarification strengthens feelings of fear, uncertainty, insecurity, as reported by Marcos.

> (…) when they went to the children's room, where they put them in those things to warm them up, the doctor told me she looked a bit dark. As if it was lack of oxygenation, so I

> was kind of scared… She started shivering and she wouldn't stop. And then, the doctor said, "I'm beginning to find her color strange, as if she was a child that was lacking oxygen. I started to get frightened. (Marcos, 36 years old, 1st daughter)

The fathers' and mothers' reactions at the moment of the exam result can be a very confusing moment, filled with doubts and uncertainties regarding their future and their child (Flakencabh, Drexsler & Werler, 2007). The period that goes from hypothesis to confirmation points to new expectations; among them, a wish that it's nothing, and everything will be resolved magically. Marcos talks about the hope he had that his child was well, and the doctors were mistaken regarding the suspicion that something was wrong. João questions his team's "guessing" about a possible diagnosis, as the below accounts describe:

> (…) I was hopeful that she would be able to hear, you know? I wish it'd been wrong. That was my hope, and as time passed by, and more examinations were made, my hope was becoming weaker, and we began to see that they were actually right. (Marcos, 36 years old, 1st daughter)

> (…) diagnosis with an exam that proves… This took a month, or a month and a half after she left the hospital… When she was born, he told me about it, and then we did a test, and it took about a month and a half for the result to come out… two months. (João, 39 years old, 1st daughter)

The grief period for their prior expectations can be reflected in the parents' projections on their children. With the new imposed reality, this mother and this father feel ashamed, suffer a self-esteem blow, which is usually followed by a guilt feeling. The impact of the birth of a disabled child raises doubts in parents about their ability to act and do something good, which may compromise, in some cases, the formation of a bond, the child's acceptance, and their ability to understand information. The news changes the course of this family's lives radically, as well as the organization of their routine, their dreams and projects, and their leisure (Sá & Rabinovich, 2006).

Thus, the faster she receives the news of their child's disablement and de-idealize the one that existed only in her mind, the higher the chance that the child and its parents have to become healthy and develop. What is only in an ideal world becomes a disconcerting reality, which brings a lot of pain and suffering. The family must welcome the facts and find meaning in this new reality (Aerts & Ganzo, 2012). After the news, despite its not being to elaborate, the couple and the family must make meaning of everything they are dealing with and everything they will deal with. They seek help to process the impact caused by the arrival of their child increasingly earlier.

The impact of the arrival of a disabled child

Every disabled child needs a welcoming family; however, a disabled child needs much more nurturing, patience, and love. After the news, the family goes through different stages, as follows: shock – which occurs when they receive the news that the child has a disablement; denial – when several families ignore the problem or question the veracity of the diagnosis some time after they receive the news; reaction – when the family experiences several feelings (such as irritation, guilt, and depression); adaptation – when the parents feel calmer, have a more practical and realistic view of the situation, and they try to organize themselves and find their own way to be able to help their children (Paniagua, 2004). In total, after the denial that a child may have some type of disablement, comes worries, adaptations, and fear-related feelings.

> (…) It is a form of grief, "Why has this happened to me? God is punishing me." This taps into your faith side to see if thing will be solved, too. We try everything, even what we don't believe in, to see if it will fix it. What you want is to mask reality, escape the truth. We got to go to several places, "This is wrong," pray, let's go to this church, our families are faithful. In the beginning, when we found out, everyone would pray, "Someone saw in the cards that there's nothing," "That's a jinxed spirit." The despair of a father and a mother is so big that you look for everything that is at your reach. It doesn't matter if you don't believe it. If they tell you that if you go there, your child will get

> better, you won't think twice! The solution is finding results… (Marcos, 36 years old, 1st daughter)

> (…) it was horrible, man! An anguish, something pressing you, and you just can't… I don't know, a really bad feeling! I'd never felt that. And my wife would tell me – my daughter is so beautiful… and I was like, "Wonderful, look at her eyes…" But then you have that idea of those children with Down syndrome that can barely move… You think of the worse! Really! This is our reality. You think of the worse, you think your child won't be able to live properly, and now, as years go by, you start to realize that it isn't like that… You experience that. There nothing like practice to give you a real situation and what will actually happen. (João, 39 years old, 1st daughter)

These stages are not experienced as a process in which after the initial shock is overcome, life will continue without problems. This grief, a feeling of loss and psychological suffering might happen again at key moments of a child's like: when they learn to speak and walk; the first time they go to a birthday party; the moment they go to school, and later, in adolescence, and so forth. The family will have several difficulties to face that go beyond care. These are also associated with the loss of idealization of their child and all questions related to accessibility to public and health services (Oliveira, Galvão & Caires, 2020). Their development will not be the same as the other children and adjustments, and adaptations will inevitable be needed (Glat, 1996).

Each phase will need reorganization of the family structure to be able to provide for the child's needs. Each moment after the child is born demands rearranging of everyday activities and the family's adaptation to a context of demands in terms of education and health, which frequently constrains caregivers financially and regarding the time they need to make use of to provide the necessary care (Axelsson, Granlund &Wilder, 2013).

Many parents anxiously await the formulation of a diagnostic hypothesis; others face or overcome their grief for their imagined child still during the diagnosis investigation period (Anauate & Amiralian, 2007). A way of examining this complex moment is the need to talk about and reflect upon having a disabled child. Parents must see the child, not only their disablement. When they do that, they can be surprised with the sequence of significant achievements and discoveries that will favor both the knowledge construction process and its social inclusion (Trindade, 2004). This construction exercise, with acceptance of difficulties, an outlook on potentialities shall favor families towards welcoming their real baby and respecting their specific characteristics.

The following account enables us to understand how the process of accepting the baby takes place. To Marcos, going against reality wasn't a good path, so, he "forced" himself to change to be able to welcome the mother and the child.

> When I saw that I was in the phase of not believing, I thought, "I cannot swim against the tide, I must go in favor of it" so that we can go well. For things to go well, we must take the same path. I cannot go against it. That was why I started to change. My mind was changing, and I know my daughter needs my help every time. She will need it, and we see that from other people's experience. An interesting thing is that I worked with inclusion, but you only learned about the student there. The moment you have a child with some problem, a disablement, you already talk to their parents in a completely different way because you want to see what their lives are like, you know? (Marcos, 36 years old, 1st daughter)

Having been given the confirmation that their child has a disablement, the attempts to abandon and mourn their dreamed child and understand who the child that was made, that is, what its features are, what it actually features. While logical reasoning seeks this understanding, feelings may torment parents, as we can see in the excerpts from the interviewees' accounts presented below.

> (…) disbelief, sometimes you don't even know what you're going to do! You get so nervous and frightened, we create a perfect son, "It'll be like this," but time will pass, and you see that there's no perfect son, and even if they're "normal,"

> oftentimes, they aren't what their parents want them to be.(Marcos, 36 years old, 1st daughter)

> (…) a shock. We couldn't imagine. Being like, "What will this be like?" "What am I going to do?" So many things go through your mind, like, "How will it develop?" We were so scared… And then, we were lost, but then, that starts going away, and you get used to it, you start doing your research, and you see that is not really what we thought it would be. We think that the child won't do anything, but it all depends on stimulation, pushing them since early so that they can learn. (Paulo, 24 years old, 1st son).

> You're hopeless at that moment. That was all you didn't want. Even because of what I knew about those syndromes, I knew that wasn't too difficult to happen in any family. The age thing, but nowadays, it's not so much about the age, but she was about 36 to 37 …this applies more to the mother, whose age would be a risk-factor for pregnancy, nowadays we see lots of children being born with Down syndrome. I was just a girl a 20, 20 something, so… I don't know, you're hopeless. You start thinking, what now? I'll have to find a way of raising this girl in a way that she becomes an independent adult in the best possible way so that she can get an education and be able to live with their own legs. I don't want her to be dependent on anyone. (João, 39 years old, 1st daughter)

Reacting to this moment varied among subjects. This is directly related to what constantly constitutes the subject, whether they are a father or a mother, what they had experienced until then, what they dreamed of, what they know. No family is prepared for this kind of experience, and along with the news that their child has some kind of disablement, syndrome, malformation, or other diagnosed abnormalities, their parents enter a world of uncertainties, loss of self-esteem, (social and cultural) prejudice, and marginalization (Sá & Rabinovich, 2006). This emerged in the interviewees' accounts recurrently. After knowing reality and trying to accept it, the interviewees have been building new feelings and behaviors before it.

One of the most assertive ways of examining this complex moment is the need to talk about and reflect upon having a disabled child. The APAEs play a key role in this process. Not only do they provide care and assistance to the children, but they also welcome and guide their parents (Silva, 2021). Parents must see the child, not just their disablement. When they do that, they can be surprised with the sequence of significant achievements and discoveries that will favor both the knowledge construction process and its social inclusion (Trindade, 2004).

This construction exercise entails acceptance of difficulties, an outlook on the child's and the couple's potentialities, sharing dreams and the possibility of seeking their baby and seeing themselves in this struggle was the way many interviewees found to leave suffering and face reality.

> (…) and the stories keep changing addresses because they are all the same, suffering, neglect, denial, grief (alarm ringing). You have a different point of view. You want something more in-depth about the situation. How they found out. We talk in a very informal way, "What's your regular day like? Do you see a doctor?" We keep asking parents because they are our students. We have knowledge and some cases by curiosity. In some cases, we see what we are feeling on our skin. We have a different outlook on our situation. (Marcos, 36 years old, 1st daughter)

After accepting the child's disablement, the couple starts a search for knowing their son and recognizing themselves as this child's parents. The parents start reorganizing their routine, caring for their child, focusing on providing assistance and care and forging bonds.

How families organize after the news

The birth of a disabled child can unite its parents as much it can separate them. Parents need to find a reason for that event by giving it meaning (Sá & Rabinovich, 2006). The idea that these families are necessarily affected concerning their quality of life must be reviewed. Families with handicapped children face conflicts that do not emerge as a direct result of the disablement, but due to the possibilities of their adapting or not to this situation (Nuñes, 2003; Oliveira, Galvão & Caires, 2020).

As described above, the repercussions of the family organization, as well as how it deals with their child's diagnosis, are directly related to a subject's concept of life and its challenges. Families need logistic and emotional support to move ahead and offer quality care to this child. Services that offer this type of support must consider the structure and dynamic of families to be able to help improve their emotional health and organization. The ambiguity feelings that exist in this context must be investigated, as they enable one to better understand the repercussion of this reality in a family (Loureto & Moreno, 2016).

Due to special care requested for a disabled child, parents are more likely to develop problems related to health such as: depression, anxiety, low self-esteem, and anguish (Lima, 2006). Tiredness, nervousness, irritability, anxiety, depression, sleep alterations, and even weight loss are frequent symptoms of caregivers of children with atypical development as a consequence of the stress caused by their newly imposed, unknown routine (Barros & Leonardo, 2013).

In this period of reorganizing family routines, one of the parents is supposed to be responsible for caring for their child, thus they shall forsake their professional life and studies to become fully responsible for caring for their child. The more severe the child disablement is, and the more severe their sequelae are, the more care and dedication will be needed.

Acknowledging that caregivers are a key component for the health area, especially in chronic, long-term situations, has been stimulating the problems that were presented by them. In case formal support is not provided, there is also a risk for the caregiver to become a patient (Grunfeld, Glossop, McDowell, & Danbrook, 1997; Garrido & Menezes, 2004). Especially, the parents of disabled children need to be supported and hear the suffering they experienced and their anguishes and insecurities regarding care for their child. Emotional and psychological support are essential to this family for them to be able to re-process their grief and deconstruct stigma and myths about their child (Oliveira, Galvão & Caires, 2020).

From the moment we are born, we are part of this basic social structure in which primary interactions are established to guarantee our survival. In addition, even though genetic aspects are important, the environment plays a key role in determining the behavioral characteristics of a child. (Fiamenghi & Messa, 2007).

According to the analyzed data, choosing one of the parents, father or mother, to either integrally or partially dedicate themselves to caring for their child is an agreement made considering the couple's reality. One of them usually needs to forsake their professional life, at least in the beginning, to be able to provide their child with the necessary care. This is a departure from a previous routine to configure an unexpected routine that tends to be tiring and demanding. Ana stated that she organized herself to stay with her son at his first stages and offer him all needed care. This demands time, as there is always a professional to look for: a pediatrician, a physical therapist, a speech therapist. Bruna was not able to return to her normal life and work outside her home because caring for her child is too demanding. She feels alone on this road. Alana said that she needed to stop thinking about herself to think about her baby. The statements below describe how demanding having a disabled child is especially for women, principally in the first years of its life, as caring for a child causes an impact on the lives of the couple, their other children, and their whole family.

> (…) when he came to me, I thought I needed to be around him. Because he has this need, he must go to physical therapy, do follow-up and reinforce that at home, his diet must be specific. However, I follow my plans. I am getting a driver's license, and in June I want to get back to studying… I was doing a vocational course in nursing. I know that one day he'll grow up, he'll have his own life and be independent. As a mom, I have to have my own life, my plans, my dreams… (Ana, 35 years old, 2nd pregnancy)

> (…) I am the one who takes care of him, all by myself. I am the one who takes him to the doctor. I am the one who doesn't sleep. I am the one who copes with his crying. I take over everything, he never does! Of course, I can't work. I've tried to leave him with people, but I'll have to leave because he's crying, screaming… I've always tried to work. I've never liked not working. I've even told my mom that I thought I was going crazy because I couldn't take this home routine anymore. I want to work and have a normal life; I

> want that, but that is not my choice. I can’t do this. (Bruna, 23 years old, 1st pregnancy)

> (…) I had to stop thinking about myself. If she hadn’t had the baby, I might have changed that, too. One thing is when a baby is still in my belly, but that’s still you around there, right… Telling your body, coordinating everything, and when you’re born, you aren’t a human being who needs you unconditionally, and you end up becoming selfish and because my daughter is special, even more… You even have people who speak – stop a little, think about yourself, and she’ll go on her own. (Alana, 38 years old, 1st pregnancy)

After a family is organized with a new and challenging routine, the couple starts looking at the children’s future. They think of all the problems that shall arise, and they think that the future will present them with new demands and requirements, as described in the account below:

> “Normal” people usually want to stand out. Imagine a person with disablement or a severe intellectual disability, if they will study, learn to read, all of this comes to mind… We kept on thinking, and the future is in God’s hands, but this accepting, understanding thing… I already understand it. It has taken me a long time. (Marcos, 36 years old, 1st daughter)

Nonetheless, when one looks at this family and each representation of the subjects belonging to this micro-system, as well as the roles that were taken on, one must understand that at each new moment, there shall be needs to be dealt with. Fear and uncertainties shall remain at each new problem. When it comes to disabled children, the health and education teams must see the family nucleus and plan interventions that shall strengthen this child’s development. This entails promoting its healthy development throughout its life, considering individual differences, interpersonal changes, and family, social, cultural, ecological, and historical contexts. To understand the development of a child, one must, above all, learn about their primary context of development, that is, their family (Lerner, Fisher, &Weinberg, 2000).

The parents of disabled children also go through several changes in their lives, such as changes in their professional lives, a decrease of their free time due to an overload of care with their child, which turns the daily life of several families into something exhaustive that demands exclusive dedication to children; the emergence of several feelings both in relation to their new child and other family members shall be assimilated and projected into the greater good of the new life that shall require a unique perspective and commitment from caregivers (Silva & Ramos, 2014). As highlighted by the accounts below, the more complex and anguishing the parents' renunciation after birth was, the more complex and anguishing their fear will be when this care structure that their family built cannot care for their children's needs. To Marcos, the person who they imagined that they could help them tend to be the one who helps the least. Consequently, their need to reorganize emerges again, bringing suffering and insecurity, as highlighted in the following account:

> It always happens, we see that all the time. The person you think will help you is the one who helps the least… We think we won't last forever… I've accepted everything that's happening (quavering voice), but what I think about the most is the future of my child. It isn't today. I know that we're alive (cries), but it's tomorrow, that's what stays in my head… tomorrow, as it will be, if she'll be independent, if she'll depend on someone, if she'll have someone to help, you know… the world is cruel. (Marcos, 36 years old, 1st daughter)

The interviewees stated that there is a moment for knowing their son in his real condition. There is a moment for adaptation before this reality. But there is also something greater: the affection that is reborn after this child is re-produced, as they see him by their unique features. It is touching to see how lovingly João talks about his daughter. The account below was given by this father with much emotion.

> (…) I love my daughter, you know, I have no other children without Down syndrome, so I don't know if this syndrome makes

> a difference… To me, it doesn't. I love my daughter, I'm crazy about her. I'm so much happier today… I used to hear, "You've got to become a parent, you don't know how good it is…" And I was like, "What?" It's just so comfortable. I arrive, have my schedule, I want to leave on the weekend, I leave, single man's life, you know how that is. We don't commit to children or anything like that…. But this commitment is so good today. You've got to be a father and a mother to understand that. You can't talk about that to someone who isn't… This changes your routine, you sleep feeling tired, you wake up tired, you're by her side on several nights… The girl won't sleep. We get really worried, but it's good… All of this is good. I'm so happy! (João, 39 years old, 1st daughter)

After re-producing a child and looking at it without seeing their disablement only, this family experiences a rebirth. The child is associated with renunciation, restructuring, bond forging, and a search for understanding. It evokes a feeling of responsibility that is not linked to guilt alone, but it is also linked to guaranteeing quality of life and happiness to its child, transforming each cycle into a restart and constant evolution.

Closing remarks

The path from the dream about an imaginary child to the reality of having a disabled child is intensely filled with feelings and small feelings. The interviewees talk about the time they needed to accept and know their child and love them. They report the need to reorganize themselves family-wise in order to provide their child with safety and the necessary care. There are several moments when someone must take their child to doctors, exams, health services, and physical therapy. At least in the first years, it is too hard for the family to be able to reconcile this forms of care with the life that they would lead before their child is born.

The whole path of the parents and the first micro-system of all children, the family nucleus, as described in this study, must be understood in order for specialized services to be made possible at different moments experienced by families. Informing that a child is disabled or that there is a suspicion cannot be done in mechanic, de-humanized way. There is a person, a family, and several expectations in this process. There is a need for listening to feelings that permeate this moment. Therefore, it is really important that teams are welcoming to families with regard to their therapeutic plans and help them face this project. Likewise, throughout this child's development, one must identify and respect the needs and specificities of the child and their family. This facilitates the creation of bonds that strengthen the relation of their teams with their family and the child and helps the team in their interventions and finding solutions that will favor everyone's quality of life. The earlier this happens, the higher the chances are for these children to develop.

This study presents the organization of the family after the news of child with disablement, and with it, the several demands for dealing with problems and providing care for the child. Radical or partial changes are agreed between couples, and several necessary responsibilities are established. One of them will take direct care of their child, and the other one will provide costs for their family expenses.

The interviews suggest that there is something to consider in the therapeutic plans of the children and people with disablement, which is an emphatic look focused on understanding everything that this family has dealt with. These families have been experiencing fears and uncertainties regarding the future, facing prejudicial, labelling contexts, and often forging a shield to defend themselves, which is only removed when they find someone willing to understand what they keep to themselves.

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