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The feelings and experience of a mother facing Down syndrome

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ABSTRACT. This study described the feelings and experiences of a mother that has a child carrier of Down syndrome. This was a descriptive study with a qualitative approach of the type of case study. The subject of the study was a mother who has a daughter with Down syndrome. Data collection occurred by a semi-structured interview and non-systematic observation, from July to December 2008, during five meetings, scheduled in advance. For analysis, all the material was categorized by extensive readings and highlighting significant terms for the information encoding. Then, the questions used in the data collection were classified in sequence topics: Mother's perception facing the diagnosis of Down Syndrome; The meaning of the concept risk baby; Explaining the Down Syndrome through religion; Mother's perception regarding the care of the risk baby. The mother has not only difficulties to accept the child's situation, but also in relation to the care, justifying the need of health professionals to seek to assist these families to understand this diagnosis, minimizing their anguish, guilts and anxiety.

Keywords: Down syndrome, mother-child relationships, risk factors.

Sentimentos e vivências de uma mãe frente à síndrome de Down

RESUMO. Objetivo deste estudo foi descrever os sentimentos e vivências de uma mãe que possui um filho portador da síndrome de Down. Tratou-se de um estudo descritivo com abordagem qualitativa do tipo estudo de caso. O informante do estudo foi uma mãe que possui uma filha com síndrome de Down. A coleta dos dados ocorreu através de entrevista semi-estruturada e observação não sistematizada, durante cinco encontros, agendados previamente no período de julho a dezembro de 2008. Para análise, todo o material foi submetido a um processo de categorização com leituras exaustivas e grifos de expressões significativas para a codificação das informações. Em seguida as questões utilizadas no instrumento de coleta de dados foram ordenados em tópicos seqüências: Percepção da mãe frente à revelação do diagnóstico síndrome de Down; O significado do conceito bebê de risco; Explicando a síndrome de Down através da religião; Percepções da mãe em relação ao cuidado com o bebê de risco. Percebeu-se que a mãe apresenta dificuldades não apenas de aceitação em relação à situação da criança, mas também em relação aos cuidados com ela, o que justifica a necessidade dos profissionais da saúde buscarem estratégias para auxiliarem estas famílias a compreenderem este diagnóstico, minimizando as angústias, culpas e ansiedades dos mesmos.

Palavras-chave: síndrome de Down, relações mãe-filho, fatores de risco.

Introduction

Generally, the birth of a child is surrounded by many expectations and celebrations, as well as doubts and anxieties concerning health, life and future. These feelings are intensified when parents are notified that they have a disabled child. In such situation, the parents often encounter difficult periods, due to the emotional factors (LEMES; BARBOSA, 2007).

The family will have to prepare the death of the idealized child and this implies to deal with a child that does not fit into the pre-established normality parameters, that is, the birth of the different leads to stigmatization. In such case the imaginary takes over

of the parents or guardians' attitudes, and the familiar dynamics becomes weakened. Arise the insecurity, guilt, the fear of the future, the rejection and the revolt, once these parents realize that, from the installed disability, they will have a long and difficult way for fighting discrimination and isolation, of both child and parents (LUIZ, NASCIMENTO, 2012).

The Down syndrome has ancient records in the human history, being the first records dating from the 19th century. The denomination Down syndrome was only proposed after many other denominations have been used: imbecility, mongoloid, mongoloid idiocy, fufuraceous cretinism, congenital acromicria, poorly done child, unfinished child, among others. Obviously,

some of these terms present a high pejorative degree, including the term mongolism, which was widely used until 1961, when the criticisms contrary to its use have emerged. As consequence, this terminology was suppressed in publications of the World Health Organization (WHO), after 1965, prevailing then the denomination of Down syndrome, although the term mongolism is still used in daily conversation (SILVA; DESSEN, 2002).

This syndrome is the genetic alteration of greatest occurrence worldwide, and generates several organic problems and also mental disability (COUTO et al., 2007). However, for many families this syndrome is still an enigma, in general, people are unaware and before a case in family they feel unsafe and fragile (SUNELAITIS et al., 2007).

When the disability is revealed, the entire family begins an adaptive struggle to restore the balance. Although only one family member is disabled, all others are affected and, to a certain extent, unable due to the problem (BARBOSA et al., 2008).

Importantly, the family life changes before the emotional demands and the living with the disabled child, may cause conflicts and emotional instability.

However, the family plays the role of both the driving force and the inhibitor of the individual's development process, considering the environment characteristics, as well as the family relationships established in the individual. The family is the first mediator between the individual and other micro systems and the culture, transmitting the cultural meanings for members of the group over generations (PEREIRA-SILVA; DESSEN, 2007).

Knowing the importance of the family for the child carrier of Down syndrome, as well as the difficulties in the family acceptance, this was the motivating factor to perform this study, whose aim was to describe the feelings and experiences of a mother who has a child carrier of Down syndrome.

Material and methods

This is a descriptive study with qualitative approach on the type of case study. The qualitative approach enables the researcher to understand how the individuals think, feel, and act before the experienced situations, according to their own perspectives. This approach seeks to understand the expressions of feelings, values, fears and attitudes, which explain the actions before a situation or specific problem (PRAÇA; MERIGHI, 2003).

The case study is an empirical approach for the analysis of contemporary phenomena within the context of real life, especially, when the phenomenon and the context are not clearly defined. This approach

has been used in all academic areas, because allows a significant holistic investigation of events of the real life, such as individual life cycles, organizational and administrative processes, changes occurred in urban regions, international relationships and maturation of some sectors (YIN, 2001). Also it intends to report a specific setting that may works, as an initiation of an analysis with the objective to seek the strengthening of wider social relationships or a particular object of study, bringing a contribution to the knowledge in nursing, because values the human subjective questions, prioritizing people in their individualities, in the relationships with the everyday lives which, articulated to the socio-cultural processes of their life contexts, allow to join the lived experiences by people according to the meaning they attributed themselves to this livings (KIMURA; MERIGHI, 2003).

The study informer was a mother with a daughter with Down syndrome included in the research project entitled "Conditions of life and health of babies at risk and their mothers in Maringá, Paraná State, throughout their first year of life". The data were collected through a semi-structured interview guided by the questions: What could you tell us about a baby at risk? What are the facilities and difficulties for you to care of a baby at risk?; and non-systematic observation, in the period from July to September 2008, during six home meetings, which were previously scheduled with the mother via telephone, respecting her choice as to the best hour and day for the interviews. The first meeting occurred fifteen days after the birth, the second with forty five days, the third with three months, the fourth with six months, the fifth with nine months and the sixth with twelve months. All interviews were recorded and then fully transcribed and the observations written in a field diary. For examination, the interviews were fully transcribed and then all the interviews and field diary material was subjected to a categorization process with exhaustive readings, highlighting the significant expressions for encoding the information.

The study was conducted according to the established by the Resolution 196/96 of the National Health Council as regards the secrecy, anonymity, informed consent and the participant right to withdraw at any time from the study. The project was approved by the Research Ethics Committee on Human Beings of the State University of Maringá (Legal Opinion no. 451/2008). The mother signed the informed consent form in two copies.

Results and discussion

The mother under study had 30 years old, is professional autonomous, with graduation in

nutrition. To ensure the anonymity, her name was replaced by the codename 'Esperança', chosen by her in the belief that since the moment that she knew the daughter diagnosis she had hope that she could have a life of quality. Her family is formed by her, the husband of 43 years old, a restaurant administrator, a daughter of 1 year and 10 months old, the maternal grandmother and paternal grandfather and the newest member of the family, 'Vitória', fictitious name chosen by the mother for considering that her daughter is already victorious because struggles for life every day. All the family members live together in the same household.

Esperança said that the pregnancy was unplanned, but when she found out she became very happy and concerned at the same time, because she has depression since the age of 18 which worsened during the pregnancy of the elder daughter, because, at the time she was forbidden to ingest any medication to control depression. Her concern was the new pregnancy and the possibility of a new interruption in the treatment which could lead to harm her mental health. This, however, did not happen because it is unnecessary to interrupt the medical treatment for depression throughout the pregnancy.

In order to facilitate the results interpretation and discussion, the questions of the data collection instrument was translated as sequence topics, which resulted in four categories: mother's perception facing the diagnosis of Down syndrome; baby at risk a concept under construction; explaining the Down syndrome through religion; mother's perception regarding the care with the baby at risk.

Mother perception facing the diagnosis of Down syndrome

The revelation of the diagnosis occurred prematurely, because the mother began the prenatal care from the beginning of pregnancy, and as she had a health plan on the occasion of the requested routine examinations, the ultrasonography was also requested. The mother reported that when she was around 12 to 14 weeks pregnant she performed the first ultrasonography indicating a possible diagnosis of Down syndrome (DS), however it was still a questioned diagnosis which was confirmed few months later after the second ultrasonography and in conjunction with the Down syndrome also was confirmed the cardiopathy diagnosis.

Due to the advanced technology, the research to identify the Down syndrome can be done prematurely, even during the pregnancy in the period between 11-14 weeks of pregnancy through measures of the liquid space at the nape of the fetus

neck, called nuchal translucency (NT). This test has high sensitivity (80%) for the main trisomies and has false-positive of 4.5%. A NT value lower than 2.5 mm reduces the risk of trisomies, as well as value equal to or higher than 2.5 mm increases the risk. The use of the program developed by Nicolaides at Fetal Medicine Foundation of London which associates the NT with the CRL (crown-rump length) and the maternal age has increased the results sensitivity. The morphological USG allows identifying the fetus phenotypic alterations already described previously, such as: bone changes in hands and fingers (short and broad hands, clinodactyly, hypoplasia or absence of the middle phalanx), short femur and humerus, increase in the interocular distance, low-set ears, brachycephaly, macroglossia with mouth ajar. Also allows the identification of related alterations such as: heart defects (CIV), polyhydramnios, encephalocele, duodenal atresia and omphalocele (MONTENEGRO; REZENDE FILHO, 2010).

Other antenatal method to diagnose the Down syndrome is the amniocentesis, through the amniotic liquid containing fetal cells that, after culture in specific media, allow the obtainment of the fetal karyotype in approximately 20 days. The test should be carried out between 16 and 20 weeks of pregnancy to confirm the diagnosis (MONTENEGRO; REZENDE FILHO, 2010). The procedure possesses a risk of fetal loss of 0.5 to 1%, thus it should be carried out in pregnant women with increased risk of chromosomopathies. The absence of growth of fetal cells, after culture, prevents the diagnosis and the test must be repeated if there are still clinical conditions and favorable gestational age (MONTENEGRO; REZENDE FILHO, 2010). The time of the diagnosis to the mother was distressing, because despite knowing the possibility of premature diagnosis, and the attempt to prepare herself, in general, the mother feels guilt, and seeks justification for such event.

When the diagnosis was confirmed I cried a lot and I wondered why me? What have I done or stopped doing for this happen to me... (at the moment she held the baby tightly and wept...) (1st visit),

Becoming aware of the diagnosis of a chronic condition with many restrictions as the Down syndrome is not easy to parents, especially to mother, that shows disappointment, at the same time they struggle to elaborate the loss of the imaginary child (SUNELAITIS et al., 2007). For this reason, in general, the coming of a baby that presents some type of disability becomes a traumatic

and destructuring event that interrupts the balance of the family (HENN et al., 2008).

The testimony of this mother made clear her delusion before the possibility of an unequal, a special child, and consequently the changes and adaptations in the family life, this fact generates in the family, especially in the mother, feelings of guilt and attempts to justify such fact as if this had happen as a form of punishment by something they have done or stopped doing previously.

However, her report revealed that to be aware of a syndrome diagnosis during the pregnancy makes the future mother to experience at the same time, the doubt and the certainty about the diagnosis and begins to believe that a divine miracle or an error of diagnosis may happen:

I had hope that, who knows the ultrasound went wrong, there are so many people this happen, pregnant of twins that do not exist, a small baby is born big, who knows this could happen to me, discover the test was wrong, Gee! It would be wonderful, a blessing from God (1st visit).

The fact that this mother had experienced the diagnosis before the child birth makes the gestation, regarded by many women as magic and unique, to become difficult and full of obstacles:

Well, due to the awareness, by the ultrasound, right at the beginning of the pregnancy that she had Down syndrome, this made my gestation very troubled, mainly because, in addition to the syndrome she had a heart complication...You know I thought so now, will she be born good? Will she survive? With a good birth, how will her life be in future? Gee! This made my pregnancy a torment, a suffering (2nd visit).

At the moment of a birth there are three different babies to fathers and mothers: the imaginary baby of their dreams and fantasies; the invisible fetus, but real, with rhythms and particular personality, which gradually reveal themselves throughout gestation; and the newborn in fact, that can be seen, can be heard, can be hold. This leads to a confrontation between the idealized child by parents and the real child that now is presented, and may be exacerbated before the presence of a disability. It is worth noting that during the pregnancy the parents tend to experience, especially during the last months, fears concerning the baby future. Although such fears are present during the pregnancy, the confirmation of a possible diagnosis of child with disability is always a shock that brings on the surface negative feelings, ambivalence and rejection by parents (HENN et al., 2008).

The presence of a disability leads the parents to experience losses that can be real or imaginary; the

maternal 'mourning' or, rather, the 'death' of the idealized child, occurs as essential part of the emotional experience of having a disabled child. This 'mourning' is different, because the child is alive and the parents, at a first moment, protest against the diagnosis. When the birth of a special child occurs, exists an adjacent process of mourning that involves various stages: numbness, shock and disbelief; anxiety, protest, sadness and concern for the future (RAMOS et al., 2006).

The fact of knowing the diagnosis even before the child birth triggers a confusion of feelings, occurring alternation between acceptance and non-acceptance of the condition by the family, quite difficult to everyone, but mainly for a mother:

In the beginning of the pregnancy some questioned me how I was feeling about knowing my daughter was carrier of a syndrome, honestly I did not accept and I could not believe, but never occurred to me the idea to cease the pregnancy, it is against all my religious principles and principles of life, of human being, if someone have to take away somebody's life this must be done by God, not me (2nd visit).

The attitudes of those are part of the closest context, in particular the father, are very important to consolidate this acceptance:

My husband was very important, I think he was always more conformed than me concerning her situation, he is the one that helps me to take care of her in many times, and I notice that he seeks to make no distinction between my elder daughter and her, I have the impression that he accepted the situation better than me (2nd visit).

The father acceptance can helps the mother to incorporate quickly the new situation. It can be noticed that, in general, in cases of births of 'imperfect children' the mothers usually embraces all the care, often by the fact that they believe that the guilt belongs to the mother; other relevant factor is the fact that many parents do not accept this new condition leading them to abandon their home. However, when the father plays the role of carrier as in this situation, this comes to help the mother to accept and reduce her feeling of guilt.

It is highlighted that in fact the vision of father as someone who plays solely the role of provider for the family and the children has been replaced by the perception that he is a member that can exert numerous significant roles, among them the companion, protector, carrier, model, adviser and teacher (HENN; PICCININI, 2010).

The birth of a child with Down syndrome reaches fathers in different ways, interfering both in the involvement with their children and in their

experiences of paternity. However, despite the difficulties, both objective (financial, time, employment), and more subjective (acceptance, sadness, preoccupation), many fathers have demonstrated good adaptation to the child with Down syndrome, able to exert well their role of fathers (HENN; PICCININI, 2010).

Baby at risk a concept under construction to mother

The risk factors to health are a constant in the human being development, which may occur before, during and after the birth (RODRIGUES, 2003). As observed in the statement below that the mother has clearly this concept:

Baby at risk would be that baby who presents some disability, of pathological nature with risk of worsening which can lead to death... (1st visit).

The main risk factors that can occur before conception are: maternal factors such as the presence of disability in the family, stillborn, premature babies or abortions, blood incompatibility, low fertility, age of mother (more than 40 years old, less than 15 years old), diseases during the pregnancy, exposure to x-ray, use of drugs, smoke or alcohol, excessive ingestion of medications or vitamin A and B, psychiatric disorders, gravidic toxemia, multiple pregnancy, hypertension and epilepsy, psychological factors such as the non-acceptance of pregnancy; social factors such as the very low family income, lack of medical assistance in the prenatal care (RODRIGUES, 2003).

Regarding the perinatal factors of risk we highlight (a) the delivery conditions: long labor (more than 18 hours), early birth, abnormal presentation of the baby, use of forceps, prolapse of the umbilical cord, anesthetic depression, premature or late rupture of the placenta; (b) the baby conditions: extreme premature with or without disease, post-mature with pronounced characteristic of malnutrition with weight, at birth, lower than 2500 g, hyperbilirubinemia in the first 48 hours of life, hypotonia, hypertonia, abnormal size of head, presentation of convulsions or convulsive components, gross tremors and/or pronounced excitability, baby impregnated with meconium at birth, with chronic or acute anoxia, reduced cry, abnormal responses to reflexes, breathing difficulties, mucus excess or salivation, gastrointestinal symptoms, generalized oedema, tensioned or arched fontanel, pronounced jaundice and/or with neurological signs, syndromic face, gross anomaly, apnea or any other type of respiratory

problem which occurs at birth, such as dyspnea, requiring the use of oxygen (RODRIGUES, 2003).

Among the postnatal factors of risk we can mention two types: a) the baby conditions: intense diseases, clinical manifestations of congenital abnormalities that were not diagnosed in the prenatal period, reduced reaction to sound and visual stimulation, lag in the motor, verbal, or adaptive, development, weight and height below the normal, pronounced dehydration and malnutrition; b) the social conditions: abandonment and maltreatment, family disorganization, inappropriate organization of the physical and temporal environment of the residence, presence of stressful events for life and reduction of positive affective interactions of mother and child during the early childhood (RODRIGUES, 2003).

Thus, the concept of baby at risk means the association of factors of risk that can occur before, during and after the conception which can harm the growing baby and the development, and even lead to death.

However, despite the mother conceptualize the term baby at risk, when questioned about her daughter being or not a baby at risk it is noticed that, at first, the denial of the fact:

[...] .[stopped and remained for quite some time thinking, after then she said] Yes, you could say that (silence for a few seconds) ... many times we don't want to believe because no one wants to believe and take things in stride, because the heart problem is not that simple, things may go right with the surgery but may go wrong as for a normal person, she is abnormal by having this defect (she refers to Down syndrome), but from the moment it is necessary to take every care, runs a bit of normality... (1st visit).

When the mother said "Yes, you could say that" it is observed that the parents, in general, need some time to assimilate the new situation, that is, to destroy the idealized dream of the perfect baby and to construct in their minds and hearts the real baby, the baby with disability.

Seeing themselves with their children with Down syndrome, they feel a huge pain that, at first, seems to be eternal. The pain resembled them the mourning pain. We may think the mourning is related not only to the loss of the idealized child, but to the feeling of maternal failure by generating an imperfect child. As if the women mourned by their maternity, by feeling unable to generate a perfect life (COUTO et al., 2007).

The Down syndrome diagnosis turns into a landmark in the family life, triggering a reorganizing process which involves five stages. In the first stage,

it is observed the shock; in this moment, many parents told that this initial period was a time of irrational behavior, with much crying, feeling of helplessness and, occasionally, a yearning for run away. In the second stage, it is observed the denial and many parents try to escape from the information of anomaly of their children. In the third stage, it is observed intense emotional reaction, sadness, anger and anxiety. In the fourth stage occurs the adaptation of parents, in which they begin to involve emotionally with the baby. In the fifth stage correspond to a family reorganization. Besides the classic feelings and the difficult to accept the diagnosis, still exists the ongoing quest for the syndrome cure (CUNHA et al., 2010).

Explaining the Down syndrome through religion

When facing an 'imperfect' child, it is not uncommon that the parents question their beliefs, their faults, seeking an explanation to the situation they are living. We can observe in the following statement, the importance attributed to religiosity to explain the Down syndrome, in the mother's view.

[...] thanks to the Spiritist Doctrine that I'm accepting and understanding the fact my daughter is carrier of Down syndrome and possesses a cardiopathy [...] my religion says that the explanation for a daughter with Down syndrome is because in one of my past lives I aborted this same girl and now she returned with syndrome for me to give her the right to live and take care of her (1st visit).

The Down syndrome is a chromosomopathy, that is, a disease whose global clinical frame is explained by an imbalance in the chromosomal constitution; however, it is verified in the speech a supernatural conception of destiny for the Down syndrome nature (BOFF; COREGNATO, 2008).

With origins in the medieval period, the disease was associated with the idea of premium or punishment to mother or son, and even understood as demoniacal possession. Visions of religious and superstitious nature were associated with the Down syndrome nature, being attributed the existence of the problem to the divine will or destiny evidencing the need of the mothers to attribute the responsibility of the phenomenon occurrence to something or someone, relieving them of a possible feeling of guilt (BOFF; COREGNATO, 2008).

However, despite the family seek explanations in religion regarding such event, it is observed that sometimes mainly in the most difficult situations they question the religion again and seek a supernatural explanation to what happened to their child:

[...] You know, sometimes in my prayers, I know it is wrong, but I question God, because I'd like to know why me and my daughter, my religion helps me, but sometimes I weaken, I don't understand why to mistreat a baby so small and besides the syndrome has such a serious problem as the heart problem, it is not easy (2nd visit).

The search for a religious explanation to a difficult situation is the way that many families use to explain their non acceptance to the new situation. In this moment are frequently cited God, spiritualism, spiritism and philosophy of life (BOFF; COREGNATO, 2008).

Mother's perception regarding the care with the baby at risk

To mother the care of a 'normal' baby is able to generate major concerns, fears and insecurities, but these feelings are pronounced when this baby is considered at risk:

[...] Ah, let's say that I'm carrying with me much anxiety all the time; it's a quite arduous because you do not make your day calm, I'm not saying it is no longer pleasant, but you live in function of the baby, then you don't know what to do, you need everyone gathered around you, even more because I have other little I have to share the attention. I have to carry my children together, at the same time. It doesn't help only to look at the newborn because I have the other child that already understands and needs my attention, but in the moment I'm very busy in function of her (the baby) then when the baby fall asleep so I could do also, I can't because I have to devote attention to the other child, then it is quite heavy, quite exhaustive... (1st visit).

Together with the care concerns, there are several doubts related to this baby cares which increases the mother concerns:

[...] doubt is happening all the time I'm not saying I had a situation, but I ask myself what if some situation occurs, for example in case the little heart becomes weak I don't know if I'll be able to notice. The doctors say I'll notice her tired breathing, breathless, and then I ask myself if I'll be able to notice that on time, she can becomes purple, nervous, crying, breathless, and what if she doesn't regain consciousness I'll have to ask for help urgently, then I ask if it'll be possible, on time enough, to ask for help, even more about this case, her pathology, but in relation to the syndrome I'm searching materials about the syndrome... (2nd visit).

She mentioned before the beginning of the interview that the baby will be operated with 6 to 9 months and the doctor said that the heart has to become tired and then the time will come, for that reason she was oriented to observe if the baby becomes tired, purple.

Ah I'm afraid she get tired and we need to go running to the hospital despite this has not happened, this concerns me very (2nd visit).

However, in many times, the moment of the diagnosis let the parents confused and without appropriate orientation, interfering in the connection with their disabled baby and, mainly, with regards to the false expectations, influencing the acceptance process or rejection of the real child (HÖHER; WAGNER, 2006). At this point, the search for information about the disability and about how would be the progress in the child development is the strategy most used by families to confront the needs of their child (SILVA; DESSEN, 2001).

Shortly before the 4th visit, Vitória had the heart surgery, in which Esperança travelled with her and the maternal grandmother to Curitiba. Remaining there for 40 days, with the delicate surgical intervention, it was necessary to the baby to stay in the Intensive Care Unit, mentioning that occurred complications, the baby had pneumonia, taking time to come out of the mechanical ventilation.

[...] Gee! Those were difficult days, I didn't know there would be so much suffering watching her so fragile, full of tubes and pipes everywhere, the truth is who helps me and made everything was my mother (maternal grandmother), Gee! She was who cared, talked to the doctors and nurses. In the room she had fear to come near the baby, afraid to hurt her, But she made everything (4th visit).

When returning home, it is noticed that Esperança has difficulty to take the cares of Vitória, mentioning difficulty to carry out so many activities such as administering medication, to take her to consultations with health professionals, and makes clear that her mother (maternal grandmother) becomes the tasks executor.

Well, today she is fine, has recovered and I have to continue life, she occupies me, because she needs more attention, has medicaments to take, comings and goings to the doctor, physiotherapist, but it's fine, my mother stays with her and care of her, that I can also have life, because to take care of her is a quite complicated and the exhaustion is great (4th visit).

It is noticed that after the third visit there was spacing between the mother and the cares of the daughter, transferring to the maternal grandmother the large portion of responsibility, evidencing the difficulty that the mother had to accept the condition and the cares with the daughter. When questioned about her husband and about his relationship with the baby, she mentioned:

[...] Ah for my husband all is fine, he plays with her, gives much attention to the elder daughter and agrees that I have to live more and can't live only in function of her disease otherwise I could get sick, as to my father (maternal grandfather), he is the famous doting grandfather, he registered her under his name only to her have health plan, and lives in her function, almost never go out (he is retired) only to take care of her.

This statement shows that there was an alteration in the family roles, in which the grandparents took the child cares, and the parents not only agreed but wished this situation, confirming the difficulty in accept the 'special child'.

This transfer of cares reveals not only the non-acceptance of the new reality by the mother but also the search of a new life, changing profession and routines, that is, the search for the own identity, as seen in the following statement:

[...] despite of her requires my attention, I need to care of my life, of my other daughter, of my profession, I want to change of profession and I'm doing a course of surgical technician. She requires much attention, as I have to study, work, my mother takes care of her (maternal grandmother), then to facilitates, her cradle stays in my mother's room (3rd visit).

The maternal concern presents as main characteristic, the almost entire devotion of mother to her newly baby arrived to the world. It refers to a state of suspension, in which the mother and the baby are closely connected, so that the woman is sensitive at a maximum in relation to her child and, due to that, she can welcome the baby, adapting more easy to the baby needs. Such sensitivity allows her to assist the baby, not leaving her to be invaded by feeling of deprivation and, on the other hand, allows her not to behave in exaggerated manner, being anticipated to the child requirements. This because the baby needs to be brought into contact with the requirements, and, consequently, to have a creational experience of what requires. To this mother that knows to adapt continually, but sometimes fails with her baby, was given the name of 'mother good enough'. Naturally, not all the mothers can be 'good enough'. There are people that feel fear of being drained by the attention that their baby requires and deliver the task of care to another person, as there are those who immerse in this state of deliver and have difficulty to break from this state. However, the fact of the baby possesses a disability – such as the Down syndrome – also can interfere in the development of the good enough maternity (COUTO et al., 2007). And, in this

moment, they turn their attention to themselves, transferring the care of their child almost completely to other family members, mainly the child grandparents.

Such a thing makes evident in this family, because during the sixth home visit, in which Vitória already has twelve months, it is noticed that all the questioning related to her cares were reported by the maternal grandmother. During the interview Esperança, in many occasions, left the room, at any time she touched or held Vitória, and stated emphatically that due to her new professional activity (she quitted her previous profession of higher degree and carried out a technical course which she was at that moment starting to actuate) she had no time to take care of Vitória that requires many cares and therefore her mother (maternal grandmother) becomes the executor of this activity, who even retired to dedicate fully to the granddaughter.

Conclusion

Although currently the Down syndrome is well known and divulged by media with the intention to reduce the prejudice against its carriers, the arrival of a child with this diagnosis, cause in the family several questionings and feelings of guilt and powerlessness before the new situation.

The present study makes evident this fact by showing the difficulties in acceptance of the child disease for the family and the frequent search for answer/explanation to such an event.

It was noticed that the mother presents difficulties not only of acceptance in relation to the child situation, but also in relation to the cares. Which in turn, justify the necessity of professionals from the health areas (physicians, nurses, phonoaudiologists, physical therapists, among others) to seek strategies to assist these families with children carriers of syndrome in taking care and having comprehension about this diagnosis, evidently these cares will not solve but reduce the anguishes of these families.

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