



RESEARCH ARTICLE

PSYCHOLOGICAL EXPERIENCE OF MOTHERS OF CLEFT LIP AND PALATE CHILDREN IN SENEGAL

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ABSTRACT

Cleft lip and palate are the most common congenital facial malformations in the world. For a long time, research and scientific studies have focused on cleft lip and palate in order to understand more about it, but also to find support strategies for parents who are still confronted with the traumatic reality of the occurrence of a congenital malformation. However, it appears that in the sub-region and particularly in Senegal, few studies have focused on the psychological experience of mothers of cleft lip and palate children. Indeed, in all societies, the birth of a child is considered as a wonderful gift, a gift from heaven that brings joy. However, the birth of a child with a congenital malformation is a real emotional ordeal, especially in the African context where cultural aspects and the weight of social beliefs can influence the appearance of psychological symptoms in mothers. This research aims to analyze the psychological experience of mothers of children with cleft lip and palate. A descriptive design with a qualitative approach was used to achieve this objective. The random sample was chosen with 14 women interviewed, aged between 25 and 45 years. The application of the semi-structured interview allowed us to detect and analyze the mother's feelings and emotional reactions. The analysis of the mothers' experiences of their child's cleft lip and palate revealed that the occurrence of the cleft lip and palate was an unexpected event, which they considered to be strange, incomprehensible and difficult, painful, stressful and traumatic. The mothers' feelings towards their child were mostly negative and characterized by disappointment, fear, crying, confusion and anxiety among others. The mothers encountered difficulties in feeding their child, but also in accessing care. In short, this study shows that the appearance of a cleft lip and palate in a newborn creates a real emotional shock for mothers, especially those who discover it at the birth of their child, which can considerably affect the mother/child relationship and lead to psychological problems in the mothers' lives.

INTRODUCTION

Cleft lip and palate, commonly known as cleft lip and palate, are congenital malformations of the lips and/or palate that are listed as the most common facial malformations in the world. According to WHO (2016), clefts are public health problem and are among the structural anomalies that cause the majority of mortality, morbidity and disability related to birth defects and have medical, social or cosmetic consequences for the affected child and require surgical intervention. According to Herzog (2017) and Chabbey and Charpy (2018), every minute somewhere in the world, a child is born with at least one of the multiple forms of facial clefts. In 2014, the average number of births with cleft lip and palate was estimated to be 1 in 700 births in France.

However, in Africa, studies have shown that the incidence of prevalence is lower and is around 0.7 per 1000 live births (Loh and Ascoli, 2011; Bonsu *et al.*, 2018). With low prevalence rate in Senegal, the disease is not well known and is underestimated. Indeed, it is very difficult to have exact and available figures on the prevalence of the disease. However, we can confirm with certainty that it is present in Senegalese society, given the few cases recorded among adults who suffer from it. It is therefore necessary, if not indispensable, to investigate the psychological experiences of mothers with children suffering from cleft lip and palate, hence the purpose of this study.

STUDY METHODS

This qualitative study was conducted at Barthimée Hospital in Thiès during a free cleft repair campaign with mothers of cleft lip and palate children from various localities in Senegal. It is about understanding the situations and behaviors of population from a subjective analysis.

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In such studies, it is difficult to carry out representative and exhaustive sampling; the rigorous principle is to carry out case studies. Incidental sampling, which consists of going out to meet the elements that constitute the study population, was chosen. Once at the hospital, mothers were informed of the objectives of the study to facilitate their acceptance. Thus, we were able to interview 14 mothers. According to Grawitz (2001), an interview is a form of communication between two people who don't know each other, with the aim of gathering certain information about a specific object. Data collection technique used is the semi-structured interview, which aims to collect essential data on a specific issue. This consists of a verbal interaction between two people in which the researcher asks questions at the beginning and then gives the floor to the interviewee, who can also be helped by follow-up questions that address the themes on which we want to obtain information without directing the respondent or interrupting him or her abruptly when speaking. In order to ensure privacy, all of our interviews took place in a hospital consultation room, which allowed us to get to the heart of the mothers' daily experience of the malformation. The interviews took place over four days, from 3 to 6 February 2020, and were conducted in Wolof for between 15 and 25 minutes, then recorded in order to collect and preserve the information. Participants' responses were transcribed verbatim, typed and saved as Microsoft Word documents. Data processing was done using Excel 2013, Word 2013 and Sphinx version.

RESULTS

Socio-demographic dimensions (table 1): Study population was composed of 14 mothers aged between 25 and 45 years, of whom 13 were married and one was a widow.

Table 1. Demographics and profile of respondents

Variables	Number of respondents	Percentage (%)
Age (in years)		
[25-30[1	7.14
[30-35[6	42.86
[35-40[6	42.86
[40-45[0	0
45 and over	1	7.14
Total observed	14	100
Marital status		
Married	13	92.86
Widowed	1	7.14
Total	14	100
Level of education		
Not educated	10	71.43
Elementary	2	14.29
Intermediate	1	7.14
University	1	7.14
Total	14	100
Profession		
Housewife	8	57.14
Tradeswomen	4	28.58
Student midwife	1	7.14
Caterer	1	7.14
Total	14	100
Ethnic groups		
Peulh	4	28.57
Serer	3	21.43
Toucouleur	3	21.43
Wolof	4	28.57
Total	14	100

Most of mothers had no schooling, i.e. 71.43% of the sample. A small proportion had received an education. The majority of them came from Podor and the rest from Diourbel, Gandiaye,

Kébémér, Thiès, Tivaouane and Dalaba in Guinea Conakry. Most of the interviewees, representing 57.14% of the sample, are housewives, followed by mothers who engage in petty trade corresponding to 28.58%. As for the remaining two, one is a student midwife and the other is active in the restaurant business, each representing 7.14% of the sample. Fulani and Wolof ethnic groups are the most represented with 28.57% each, followed by Serer and Toucouleur ethnic groups, each representing 21.43% of the study population.

Psychological experience of the malformation

Mothers' feelings about themselves upon discovery of the malformation (Figure 1): The arrival of a child with a cleft is accompanied by feelings that can destabilize the mother's psychological state. Indeed, the majority of the respondents had experienced a shock, a surprise. Next come those who have experienced trauma, followed by mothers who have experienced feelings of guilt and pain.

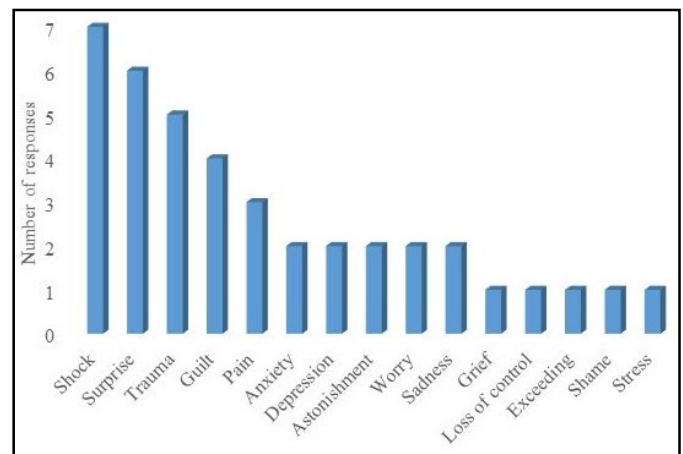


Figure 1. Mothers' feeling about themselves upon discovery of the malformation

Others were affected by anxiety, surprise, disappointment, sadness, worry and lastly mothers who felt grief, stress... Having become aware of the malformation at the birth of their child, the mothers didn't anticipate the occurrence of the deformity, which then manifests itself as an unexpected event with experiences described as unprecedented and leading to de facto trauma for mothers. P1 lamented, "I found out about my child's deformity at birth ... I found out myself, nobody told me. I was shocked. I didn't eat and I didn't even want to drink. I didn't feel like anything. I had nothing but grief and pain when this child was born". The traumatic shock suffered by these mothers is due to the unexpected nature of the malformation. They considered their child's situation as shocking, difficult to accept and causing them to feel sadness and pain. P2 confirms this state of shock to which she adds the guilt she felt "When I saw the child I was shocked and traumatized... How am I going to live with this child in this environment where nobody knows about this abnormality? I was ashamed of myself...I am the first person who brought this thing to the village". Indeed, some mothers feel guilty for having given birth to such children. And this guilt affects the inner life of the mothers of these children to a great extent and makes them search for the origin of the malformation. This feeling of guilt can lead to depression and insomnia. This is the case of P3 who says: "I spent a whole night without sleeping. I was thinking and trying to understand what was going on".

P6 follows the same line of thought, saying: "I was in a lot of pain, my throat was full of knots and I wondered what had really happened to make this girl like that". Similarly, P7 said: "I was wondering if I had done something or if I was perhaps ill. I felt guilty wondering if I had done something wrong or said the wrong thing to someone to the extent that it would reflect on my child". Above testimonies show the intensity of the pain and the complexity of the mothers' feelings when faced with this unexpected situation, which is considered strange, incomprehensible and difficult to accept.

Mothers' feelings about their child (Figure 2): The birth of a child is usually supposed to be a time of pure joy and happiness where negative feelings have no place. But when it comes with an anomaly, it undoubtedly brings mixed feelings. Mothers have been challenged and have expressed various feelings about their child.

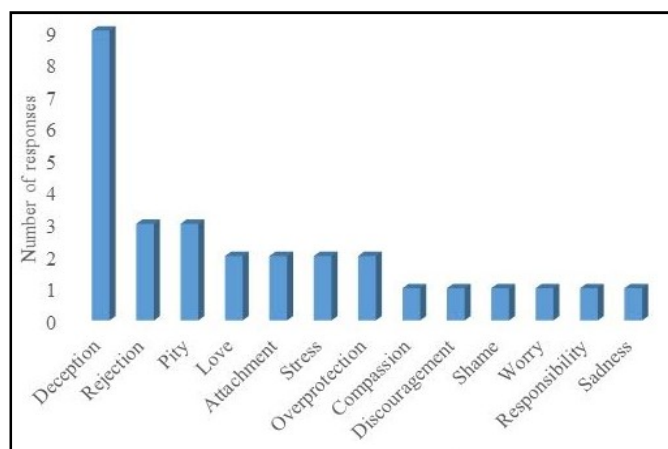


Figure 2. Mothers' feelings about their child

Figure 2 above shows that the majority of the respondents experience sense of deep disappointment about having child with malformation and feel pity or rejection towards their child. Feelings of stress, discouragement, shame, sadness and worry were highlighted. On the other hand, attachment, love and responsibility animated some mothers. It emerges from this analysis that mothers' feelings are mostly negative and characterized by disappointment. Mothers expected to give birth to beautiful, healthy children. This is what P3 explains: "I was happy after the birth. But when I saw that my child was missing something, I was disappointed..."

P13 also shared: "I really didn't expect a child who is deformed. It was a surprise to me.

I have never seen one and I didn't even know that these kinds of children exist". The lack of information about clefts can also increase the severity of the disappointment. Mothers are not aware of this malformation at all.

Pity that mothers evoked is tinged with a feeling of guilt, of sadness that refers to a self-blame for being the one responsible for what happens to the child and for all that he will experience in the future. It is in this sense that P14 says: "Looking at the child, I was sad for him because of his situation. And I was thinking about how this child will live in the future. Will he be able to be and flourish like the others?" Guilt in this case helps to reduce the impact of the trauma. In fact, by feeling guilty, mothers partly master the trauma and the situation becomes easier to manage and to appropriate.

This state of affairs can appear conciliatory and allow the mother to accept the situation: "This is my first child despite his malformation, I consider him a part of me. This child needs me more, that's why I protect him a lot. I don't even want him to cry. I pamper him so that he doesn't feel rejected" P3.

P12 also states: "I felt sorry for my child, you know if you give birth to a sick child, you get more attached to him than to the others because he is a part of you and you have to take care of him. We detect through these shares the feeling of overprotection, love and attachment of the mothers towards their child as if they thought they were completing what they could not do during the pregnancy. So deformity is not an obstacle for her in the mother-child relationship. On the other hand, in the first few days after birth, some mothers may find it difficult to establish a relationship with the child P3 "I couldn't even hold him in my arms when he was handed over to me... I handed the child over to them straight away. I handed the child over to them straight away. I was so confused that I asked them if it was really my child". In the case of P13, there was a refusal to look after her child because her trauma had left her unable to reason properly: "I didn't take the child, my mother-in-law did". It is therefore important to provide help to these distraught mothers who most often turn to the medical profession for comfort and acceptance of the situation. P13's words sum up those of others: "I thank God because the doctor helped me a lot. He was the one who told me that it was possible to solve the problem with an operation. I thank God because the doctor helped me a lot. He was the one who told me that the problem could be solved by an operation, that we just had to take care of the child and that he is a child like any other. It was only then that I started to come to my senses and accept the ordeal".

Mothers did not imagine that their child would be deformed: "It's true I never knew that I would give birth to a deformed child. I hoped he would be like my other children... But I love him as much as the others and I have to help him". But the maternal instinct and the ability to be a good mother make them able to give love to such children.

Emotional reactions of the mother to the disability (Figure 3): The discovery of the deformity in child often puts mothers in a state of psychological and emotional shock that is indescribable and difficult to accept. This degree of psychological damage depends on the form or type of cleft the child has, but also on the social realities in which the mother lives.

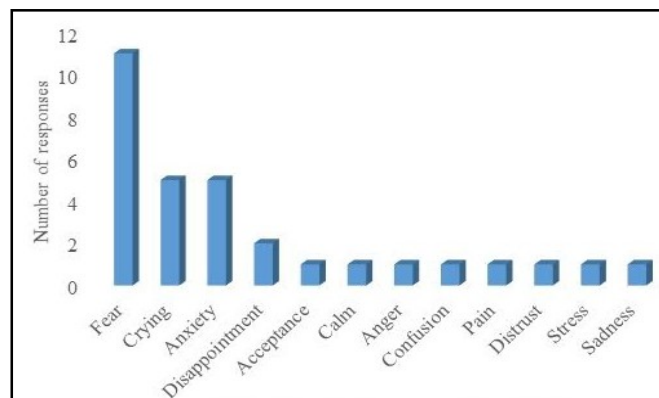


Figure 3. Mothers' emotional reactions to disability

Mothers' reactions to the discovery of the cleft are many and varied. These include fear, which is the most recurrent reaction, crying, anguish, with 11, 4 and 3 responses respectively, anxiety, disappointment, with 2 responses each, and other reactions such as stress, pain, calm and sadness, each with 1 response. The majority of the mothers felt a sense of fear when they saw their child's condition. More often than not, they are unaware of this deformity, which petrifies and destabilizes them. It is in this logic that P6 says: "... I trembled at the sight of the child's face. I was anxious to have to live with this child". P13 spoke along the same lines: "The first time I saw the child, I screamed and immediately looked away. I was afraid, I couldn't speak or hold anything. My whole body was shaking, like when you get bad news like the loss of a loved one. For other mothers, the fear they felt was that of others' gaze, as P4 said: "My problem was that I was afraid of the way others looked at me". These words reveal that mothers are also terrorized by the gaze of others who indirectly accuse them. Some mothers, in addition to the fear that results in confusion, anguish and anxiety, have cried at their child's physical appearance. Crying is the first manifestation of the traumatic shock that causes these mothers to feel sad.

Some lamented that this was their second child with a disability or the same deformity. P2 said: "I cried bitterly and asked myself why this was happening to me? Why does this child still have disability...I had another child (the eldest) who was born with wrist deformity". However, these reactions do not remain permanently fixed in the mothers. After a while their strength, mental capacity or faith calms them down and they end up realizing that they have to move on and not focus on their child's disability.

Some will say, like P10: "I cried a lot but at a certain point I resigned myself and gave in to God's will".

On the other hand, P9 said: "Ah, I just kept calm and told myself that it is God's will". This leads us to say that reactions are experienced differently from one person to another. Some do not react at all and are often stoic.

Mothers' feelings about childcare (Figure 4): Almost all the respondents were worried (11 responses), stressed (8 responses) or tired (3 responses). Feelings of fear, anxiety, discouragement, hope, powerlessness and responsibility were experienced by one mother each.

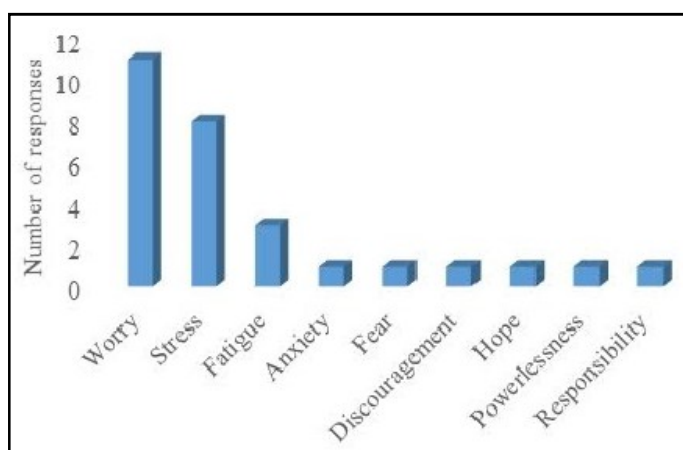


Figure 4. Mothers' feelings about childcare

In this study, the respondents expressed their concern about their child's care. They were also tired of having their child treated, as the treatment centers were generally very far from their localities.

They were often bounced from one hospital to another in search of a facility that could repair their child's cleft. In addition, they were unable to afford the cost of the repair and the hassle of appointments that never ended. P10: "My main concern was to look after my child. That is why I took him to several health facilities but each time I was sent back and told to go to such and such a health facility. I was tired of not finding a solution". What is encouraging is that all the mothers interviewed in this study consulted health workers. Only one of them had, in addition to consulting doctors, taken her child to several traditional healers in order to explore another alternative to care for her child because of the cost of care and of faith in certain beliefs. This is highlighted in P12's expression: "I went to the doctor who prescribed a special dummy for my child who was 9 months old. But I couldn't afford to pay for it, it was very expensive for me. So I went to see the traditional healers because I was worried and wanted to change the situation at all costs. Wherever I went, I was told that the child was taken by the evil spirit. Someone then told me about a man outside Dakar who gave traditional care". Difficulties feeding during breastfeeding were also reported because of babies being unable to suckle. This affected the growth of some children considerably. They expressed this in the following words: "He spent all his time crying and what I gave him came out of his nostrils. Afterwards the child lost weight and got so thin that I thought he was going to die" P12.

" And also difficulties in suckling. Finally we were asked to buy the bottle" P3.

However, strategies were found to feed these children either with a bottle recommended by the carers or with a spoon as some expressed. Some mothers also expressed concern about milk cost, which they considered to be too high in relation to their purchasing power, as they were in a precarious situation that prevented them from taking care of themselves properly. Problems of growth and weight loss in children were mentioned by respondents, no doubt caused by the poor diet of children. This is evident in the following quotes. P7: "The child could not suckle, so he was often sick and became stunted. It was to save my child that I decided to take my courage in both hands and brought him to the hospital.

P9: "... my daughter had lost weight, I was distraught. That's when I really understood the seriousness of the situation... She was also having difficulty breastfeeding. I was giving her milk with a spoon, which was very difficult to do and I think that's why she is malnourished. I wondered if my daughter would survive. We have huge difficulties in feeding the child in relation to buying the milk. It is very costly and stressful not being able to meet the basic needs of a child. Other aspects related to child development were also mentioned. These include language and hearing difficulties for these children. These difficulties most often plunge the mothers into terrible anxiety and fear, so that they probably doubt their child's future and schooling. P4: "... when I think about his future life, especially his education, I am stressed. These are children who have delay in language. ...It will take quite a long time for him to be able to speak. He may be late for school age. My first

child went to kindergarten at 2 and I don't think this one could do the same.

P3 says: "...I am also concerned about his schooling because of the speech difficulties. Everyone I've seen with this deformity has difficulty speaking.

I have seen a friend's child who has had the cleft repaired but still has problems speaking. Yet he is between 14 and 15 years old. In addition, the stress of waiting for future intervention was most commonly shared, and this was compounded by the child's fragility in the face of malnutrition and respiratory diseases, for example. This is reflected in the following comments: P8: "The wait was long and stressful. Every day I wondered if my child would survive. Now he is 3.5 years old and he cannot walk or talk. I wonder if he will ever be able to". P7: "I went back and forth to this hospital so many times for the child's treatment. They couldn't operate on him because of his low weight". Apart from that, there is the stress of the surgery. Mothers are confronted with the reality of having to leave such a small being alone in the operating room. P14 said: "... It's the operation and the waiting that are stressful ... you see when they brought my child to the operating theatre, I wasn't calm. Even if I wanted to, it's the maternal instinct that won't let me". The other stressful aspect mentioned was the presentation of the child after the operation. Some mothers expressed their hope that the physical appearance of their child would change considerably. P5 said: "We hope that the stress we feel about the child's appearance will go away once the procedure is done". For others, however, even if there is hope of a definite improvement, they are still filled with a feeling of discouragement because they see that the child's situation hasn't completely changed. In this sense, P14 says: "... After the intervention, the child continues to have problems. He often has a cold, so we are in and out of the hospital all the time. I wonder if he will really be cured.

P1 expressed feelings of discouragement because of the delivery of a second child with cleft. She said: "I was discouraged and confused that I still had to go through the difficult circuit to care for my child. You can see how I have lost weight thinking about this situation. I hardly eat at all. Sometimes I wonder what I have done to God. If I have to have children like this all the time, I think I will stop getting pregnant. I am poor, how will I continue to buy milk for these children?" Thus, the analysis of the psychological experience showed that, whatever the situation, the discovery of the malformation constitutes a real upheaval. This discovery is accompanied by feelings such as shock, despair, worry, shame, guilt and so many other emotional reactions including fear and crying that vary from one mother to another and affect her psychologically.

DISCUSSION

The main results of this study are compared with others, from which we were interested to note some similarities. It revealed number of feelings and emotional reactions that mothers may experience when their child has a cleft lip and palate. These feelings are about themselves, their child and their infant care. Indeed, most of mothers interviewed for this study felt shock, surprise, trauma, guilt, pain, among others. These findings corroborate those of Antwi-Kusi *et al.* (2015); Oshodi and Adeyemo (2015) and Olasoji *et al.*, (2007) who link mothers'

psychological symptoms to socio-cultural beliefs that would be important to understand in order to analyze the trauma. Guilt felt by mothers for having given birth to a deformed child greatly affects their inner life and often leads them to search for the origin of the deformity. These results are similar to those of Bolomey *et al.* (2013) who found that in such situations, it is as if time stands still and mothers are plunged into a state of total incapacity. And, it is in this state of manifest helplessness that shame and guilt will invite themselves and can lead to psychological disorganization. This research also shows that all the mothers were aware of the birth defect, which they considered to be an unexpected event with particular experiences that led to de facto trauma for them, as confirmed by Johansson and Ringsberg (2004). According to this study, mothers' feelings about the birth of malformed child are mostly negative and characterized by disappointment. In such cases maternal dreaming is suddenly hindered by the reality of a malformation (Grollemund, 2014).

From this study, feelings of overprotection, love and attachment of the mothers towards their child emerged as if they were thinking of completing what they couldn't do during the pregnancy. Thus, deformity doesn't constitute an obstacle for them in the mother-child relationship, even if, according to Habersaat *et al.* (2009), in the first days after birth, some mothers may have difficulties in establishing a relationship with the child. With regard to infant care, mothers expressed concern about their child's care. This is in line with the findings of Habersaat *et al.* (2009), which show that parents are afraid and concerned about their child's health or the care to be given, as the care centers are generally far from their localities. They have often been bounced from one hospital to another in search of a facility that can repair their child's cleft. In addition to this, there is the cost of the repair, which they cannot afford, and the hassle of appointments that never end. Similarly, Pérez *et al.* (2015) report an increase in the care of children with or of acial clefts. Concerns about milk costs and feeding difficulties with adverse consequences for the overall health of the deformed child have also been raised by mothers. Indeed, previous studies (Bonsu *et al.*, 2018; Johansson and Ringsberg (2004) confirm our findings.

Despite this rather difficult and restrictive financial situation, mothers consulted health workers. And one of them, in addition to consulting doctors, took her child to several traditional healers in order to explore another alternative to care for her child because of the cost of care but also because of faith in certain beliefs. In the same vein, Dagher and Ross (2004) argued that patients generally consulted traditional healers because this approach was part of their culture. In addition, different types of stress were reported: stress related to the expectation of future intervention which was best shared, to the fragility of the child in relation to malnutrition and respiratory diseases and to the surgical operation. These results are in line with those of Habersaat *et al.* (2014), who found that leaving such a small child alone in the operating room was a major source of stress for parents, especially mothers. The other stressful aspect mentioned by the mothers is the presentation of the child after the operation. Some expressed their hope that the physical appearance of their child would change considerably. However, for others, even if there is hope for a certain improvement, there is still a feeling of discouragement because the child's situation may not change completely. The birth of a child with a difference causes parents a deep narcissistic wound: a loss of confidence in their

ability to procreate, especially if this birth is associated with a first pregnancy, but also a loss of confidence in being good parents (Chané, 2015).

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