

MATERNAL FEELINGS AT CONGENITAL MALFORMATION DIAGNOSIS

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ABSTRACT. This article aims to analyze the maternal feelings about a congenital malformation diagnosis received before birth, immediately after birth, or in early infancy. This study was conducted with mothers whose children have congenital anomalies, based on ninety-seven interviews that included questions regarding pregnancy and the mothers' perspective on their child diagnosis. Regarding maternal feelings, the main questions were: 'How did you feel when you first heard the diagnosis?', 'How have you been feeling?', 'Where have sought comfort?'. Qualitative analysis was performed based on categories for data comprehension. Congenital malformation diagnosis breaks down the maternal expectations around the child's future, creating an environment full of anxiety, confusion, insecurity and multiple fears. The support of the multidisciplinary health team, religious and domestic is important to reduce the emotional impact suffered by the mothers after the diagnosis. It also helps the early difficulties in bonding with the baby.

Keywords: Mother child relations; adaptation; congenital malformation.

SENTIMENTO MATERNO AO RECEBER UM DIAGNÓSTICO DE MALFORMAÇÃO CONGÊNITA

RESUMO. Este artigo objetiva analisar o sentimento materno ao receber um diagnóstico de malformação congênita do filho nos períodos: pré-natal, nascimento e primeira infância. O estudo foi realizado com mães de filhos com anomalia fetal, por meio de noventa e sete entrevistas, que continham perguntas sobre gravidez e percepção acerca do diagnóstico. Direcionado ao sentimento destacam-se as questões: 'Como você se sentiu ao receber o diagnóstico?', 'Qual o sentimento atual?', 'Como encontrou conforto?'. Para compreensão dos dados foi utilizada a análise qualitativa de conteúdo com base numa estrutura de categorias. O diagnóstico de malformação congênita desmitifica as expectativas maternas quanto ao futuro do filho, configurando um cenário de ansiedade, confusão, insegurança e múltiplos medos. O auxílio, seja da equipe multidisciplinar de saúde, religioso ou familiar, é importante para ajudar mães a reduzirem o impacto emocional do diagnóstico, além de auxiliar com as dificuldades iniciais em estabelecer o vínculo com o bebê.

Palavras-chave: Relações mãe-criança; adaptação; malformação congênita.

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SENTIMIENTO DE LA MADRE AL RECIBIR DIAGNÓSTICO DE MALFORMACIÓN

RESUMEN. El objetivo de artículo es analizar el sentimiento de la madre al recibir, en los períodos pré-natal, nacimiento y primera infância, el diagnóstico de malformación congênita de su hijo. Para ello fue realizado un estudio con madres cuyos hijos son portadores de anomalia fetal, por medio de noventa y siete entrevistas, que contenían preguntas sobre el embarazo y sobre el impacto de conocer el diagnóstico del bebé. Direccionado al sentimiento materno, se destacan en él, los siguientes aspectos: ‘Como usted se sentio al recibir el diagnóstico?’, ‘Cual es su sentimiento actualmente?’, ‘Como encontro consuelo?’. Para poder comprender mejor los datos fue utilizada una análisis cualitativa de contenido con base en una estructura de categorias. El diagnóstico de malformación congênita desmitifica las expectativas maternas em relación al futuro de su hijo, configurando un escenario de ansiedad, confusión, inseguridad e múltiples miedos. El auxilio, sea del equipo multidisciplinario de salud, religioso o familiar, es importante para ayudar a las madres a reduzir el impacto emocional producido por el conocimiento del diagnóstico, y además servir de auxilio en las dificultades iniciales de establecer un vínculo con el bebé.

Palabras clave: Relaciones madre-niño; adaptación; malformación congênita.

Introduction

According to the World Health Organization (World Health Organization [WHO], 2017), the congenital malformation is defined as “[...] structural or functional anomalies that occur during intrauterine life and may manifest before birth, immediately after birth, or in early infancy”.

Pregnancy, for Silveira, Mota, Fernandes and Teles (2015), is an intense and contradictory phase, given the significant changes inherent to the gestational period, both biological/physical and psychic. During this period, the pregnant woman experiences different emotions: specific anxieties related to her health and that of the fetus, delivery, and the baby's general conditions at birth. Besides, at this time and sometimes, much earlier, parents create an idealized child image according to their expectations and desires (Schorn, 2013). Therefore, the diagnosis of fetal malformation may constitute the completion of a dream, reflecting on the ideal child fantasized by the couple (Antunes & Patrocínio, 2007). The context also corroborates the emergence of negative feelings of incapacity, guilt and mourning for losing a healthy baby (Silveira et al., 2015).

When the mother receives the news that her child has a congenital malformation, she goes through an emotional process that displays the classic signs of psychological mourning. Such feelings are related to the loss of the idealized pregnancy. The impact caused by the diagnosis leads to a period marked by an emotional lack of control, configuring the shock phase. It is common to deny the facts and the need to confirm the veracity of such a diagnosis. Subsequently, the beginning of the psychic adaptation is characterized by feelings of guilt, sadness, anger and detachment by the baby, also comprising questions about her competence in being a mother. Gradually, the feelings of anxiety and anguish tend to diminish. The woman enters a phase of balance until she reaches the reorganization stage when she can understand the child's situation. This sequence constitutes the stages of psychological mourning for Tedesco (1997). It may not

always occur linearly, overlapping or not existing, in addition to varying according to each pregnant woman's individuality.

Fathers are also afraid to establish an emotional bond with a child who may have a short life span. This difficulty in adapting to the new reality can trigger a family breakdown and psychological traumas (Santos, Dias, Salimena & Bara, 2011). There are several experienced adversities by the news of fetal anomaly, and the frustration of parental wishes and expectations threatens all family dynamics (Antunes & Patrocínio, 2007).

According to Roecker, Mai, Baggio, Mazzola and Marcon (2012), the earlier the diagnosis, the more time parents have to seek information, understand the child's developmental situation, and gradually deal with the feelings inherent to this condition. The same authors state that, besides the negative feelings during pregnancy, the family will have to face social issues that involve acceptance and living with a child with malformation after birth. Facing with social prejudice requires, from parents, an emotional preparation so that this condition does not affect their acceptance, coexistence and involvement with the child.

The different etiologies of the malformations, the different degrees of visible changes, prognoses and varied clinical implications demand specific care from a multidisciplinary team. As the diagnosis can occur at different times in the child's development, the mother's psychological capacity to cope, the family's socioeconomic conditions and the professional's technical knowledge must be considered when communicating the diagnosis (Gomes, Marin, Piccinini, & Lopes, 2015). The interactive process between health professionals and the mother provides psychosocial support and coping strategies so that this period of the imaginary mourning and adaptation to the new reality occurs in a less traumatic way. Equally important is the health professionals' attention to the father. According to research developed to identify how paternal coping occurs in the face of a child's congenital malformation, it was identified that men suffer as much as women do. When the team also focuses its attention on the physical and emotional health of the father, provides that he cares and supports his partner during and after pregnancy, enhancing the process of preparing the couple and, consequently, the necessary care for the child (Silva, Girão, & Cunha, 2016).

Considering the impact on mothers of children with congenital anomalies, the scientific and social relevance, and the scarcity of literature that addresses the theme, this study aimed to identify, analyze, and understand these mothers' experiences.

Materials and methods

The qualitative nature characterizes this descriptive investigation. Qualitative research as a methodological option is based on analyzing defined questions and formulate reliable explanations. When considering intrinsic aspects of social relations, which cannot be reduced to variables, this approach works with the meaning and motivation present in human actions (Minayo, Deslandes, & Gomes, 2013).

Data were collected through a semi-structured interview with mothers of children with fetal malformations. The intention was to understand maternal experiences and feelings when receiving congenital malformation diagnosis in the periods: prenatal care, immediately after birth, and early infancy. The study was carried out at the Hospital Universitário Regional do Norte do Paraná (North of Paraná Regional University Hospital), at the Instituto Londrinense de Educação para Crianças Excepcionais (Londrinense Institute of Education for Exceptional Children) and the Clínica de Especialidades Infantis/Bebê Clínica (Children Specialties Clinic/Clinic Baby). The semi-structured interview was presented in the form of a script with questions related to the family's socioeconomic profile and maternal feelings,

with an emphasis on the following questions: 'How did you feel when you first heard the diagnosis?', 'How have you been feeling?', 'How have you found comfort?'

The participants were informed about the work and signed the Informed Consent Form. Throughout the data collection, the determinations in Resolution 196/96, from the National Health Research Council, which provides about guidelines and regulatory standards for research involving human beings, were respected. The Ethics and Research Committee duly approved the research, under the number: 1,784,134.

Qualitative content analysis was used to understand the data (Bardin, 2011), based on category structures. The authors read the interviews, and the agreement was sought to define the categories and classification of responses.

Results and discussion

Ninety-seven interviews were conducted with mothers of children with congenital malformations and diagnosed at different stages of development (at prenatal care: 21 interviews, at birth: 21 interviews and at early infancy: 55 interviews).

The interviewees' age ranged from 17 to 46 years, most frequently in the 17-22 years age group (Table 1). This group, younger than 30 years, showed higher fertility, being advanced maternal age and the incidence of congenital malformations a recurrence factor in this study - a result similar to other studies, such as Vasconcelos and Petean (2009). Paternal age ranged between 17-59 years, most frequently in the 34-42 year age group, according to Table 1. A California survey (USA), which analyzed the association between paternal age and some congenital anomalies, identified a higher risk (10 to 14%) of malformations of the upper and lower limbs, the nervous system and the skin among 42-year-old compared to 29-year-olds parents (Mendes, Avena, Mandetta, & Balieiro, 2015).

Table 1. Frequency of Maternal and Paternal Age in the Diagnosis Period

| Maternal Age | Prenatal | | At birth | | Early Infancy | |
|--------------|----------|-----|----------|------|---------------|------|
| | N | % | N | % | N | % |
| 17-22 | 4 | 19 | 7 | 33.3 | 19 | 34.5 |
| 23-28 | 2 | 9.5 | 1 | 4.7 | 13 | 23.6 |
| 29-34 | 7 | 33. | 3 | 14.2 | 11 | 20.0 |
| 35-40 | 5 | 23. | 9 | 42.8 | 8 | 14.5 |
| 41-46 | 3 | 14. | 1 | 4.7 | 4 | 7.2 |
| Total | 21 | 100 | 21 | 100 | 55 | 100 |
| Paternal Age | | | | | | |
| 17-24 | 3 | 14. | 3 | 14.2 | 5 | 9.0 |
| 25-33 | 6 | 28. | 8 | 38.0 | 16 | 29.0 |
| 34-42 | 9 | 42. | 5 | 23.8 | 17 | 30.9 |
| 43-51 | 2 | 9.5 | 3 | 14.2 | 8 | 14.5 |
| 52-59 | 1 | 4.7 | 1 | 4.7 | 1 | 1.8 |
| Ignored | 0 | 0 | 1 | 4.7 | 8 | 14.5 |
| Total | 21 | 100 | 21 | 100 | 55 | 100 |

Source: The authors.

Regarding the education level (Table 2), there was a higher frequency of mothers who completed high school. According to Fontoura and Cardoso (2014), the educational level has a positive relationship with a qualified prenatal. The longer the years of education, the better the monitoring of pregnancy.

Table 2. Maternal Level of Education in the Diagnosis Period

| Education | Prenatal | | At birth | | Early Infancy | |
|--------------|-----------|------------|-----------|------------|---------------|------------|
| | N | % | N | % | N | % |
| Illiterate | 0 | 0 | 0 | 0 | 1 | 1.8 |
| IES | 3 | 14.2 | 6 | 28.5 | 9 | 16.3 |
| CES | 2 | 9.5 | 1 | 4.7 | 11 | 20.0 |
| IHS | 3 | 14.2 | 7 | 33.3 | 7 | 12.7 |
| CHS | 8 | 38.0 | 6 | 28.5 | 19 | 34.5 |
| IHE | 3 | 14.2 | 0 | 0 | 0 | 0 |
| CHE | 2 | 9.5 | 1 | 4.7 | 8 | 14.5 |
| Total | 21 | 100 | 21 | 100 | 55 | 100 |

Source: The authors. **Note:** IES: Incomplete Elementary School; CES: Complete Elementary School; IHS: Incomplete High School; CHS: Complete High School; IHE: Incomplete Higher Education; CHE: Complete Higher Education.

The most family income reported was up to two minimum wages (social class E from IBGE), reinforcing the association between low education and low economic status, risk factors for congenital malformations (Costa, Gama, & Leal, 2006). The risk is related to increased exposure to teratogenic agents, such as infectious diseases, alcohol and tobacco, a possible lack of nutrients/vitamins during pregnancy or more deficient access to health care and screening.

Feelings when receiving the diagnosis

Table 3 presents the response categories for the question 'How did you feel when you first heard the diagnosis?'

Table 3. Response categories for the question, 'How did you feel when you first heard the diagnosis?'

| Prenatal | At birth | Early Infancy |
|----------|---------------------|---------------------|
| Sadness | Sadness | Sadness |
| Despair | Despair | Despair |
| Fear | Worry | Fear |
| Surprise | Surprise | Surprise |
| | Escape from Reality | Escape from Reality |
| | | Devastation |

Source: The authors.

The diagnosis of fetal malformation inevitably causes great disillusionment for parents. Thus, the categories of sadness, surprise and despair were repeated in all periods analyzed in this research. The feelings referenced by pregnant women are compatible with several studies that also include sadness (Santos et al., 2011), anxiety and depression (Borges, Pinto, & Mos Vaz, 2015; Vasconcelos & Petean, 2009), anguish, shock and fear (Silva, Madeira, Oliveira, Lima, & Campos, 2012) and guilt (Piccinini, Gomes, Moreira, & Lopes, 2004).

It is noteworthy that, although they have their fears, at no time do parents expect their child actually to be born with an anomaly. Thus, the first manifestation may be surprise or devastation. For Reis and Santos (2011), concerns related to the possibility of death, social prejudice, chronicity and medical procedures that the child may be subjected lead to the experience of multiple fears.

The escape from reality category occurred only in the periods of birth and early infancy. It is inferred, therefore, that early communication of the diagnosis of congenital malformation is a factor that favors the acceptance of the problem. Roecker et al. (2012) share the importance of early diagnosis: this allows parents to have more time to understand the situation, welcome their feelings and face everything that is to come more adequately. Emotional preparation also involves acquiring clarity about the newborn's problem and the necessary attitudes towards this condition (Vasconcelos & Petean, 2009).

The quotes taken in full from the interviews reveal the feelings experienced by the mothers:

I was terrified ... I didn't even have any milk.

It was a shock, as I planned the pregnancy for five years.

I didn't know anything about the syndrome. I didn't know how to cope.

I was normal, but felt for the baby.

The individualized analysis of each period reveals that during the prenatal period, the categories obtained were despair, sadness and fear - attitudes related to the surprise of the news, corresponding to the first and second phases of Tedesco's psychological mourning (1997). Still, the evidence of some concrete aspects of the baby in obstetric ultrasound breaks with maternal expectations and generates some frustrations (Gomes et al., 2015). In this period, the fantasies of disability and death emerge, beginning the period of mourning for losing a healthy child (Maldonado, 2017).

When the diagnosis occurs at birth, the categories sadness, escape from reality, and worry are observed. At early infancy, devastation, sadness and escape from reality stand out. It is noteworthy that sadness is usually linked to uncertainty in relation to the baby's prognosis and the confrontation of the imaginary (healthy) baby with the real baby (who has comorbidity), which implies the experience of a state of alienation – a way of avoiding this harrowing abnormal situation for women (Brazelton & Cramer, 1992).

The following quotes exemplify the conditions experienced by mothers:

I was afraid of losing my son after being diagnosed with paralysis and doubts if I was able to take care of him.

I almost had a heart attack. I thought I wouldn't know how to take care of my daughter that would die.

My world has fallen.

Feeling at the time of the interview

Table 4 presents the response categories for the question 'How have you been feeling?'

Table 4. Response categories for the question, 'How have you been feeling?'

| Prenatal | At birth | Early Childhood |
|----------------------------|-----------------|----------------------------|
| In the understanding phase | Concern | In the understanding phase |
| Relief | Relief | Relief |
| Lack of hope | Surprise | Fear |
| Hopeful | | Guilt |

Source: The authors.

Situations that involve the health and development of the newborn with a malformation almost always generate suffering for the parents. However, according to Drotar, Baskiewicz, Irvin, Kennel and Klaus (1975), there is a progressive adaptation concerning the care and satisfaction with the child. The category 'In the understanding phase', present in the prenatal and early infancy periods, includes mothers in this process.

The mothers have particularities that will influence not only the way of living each phase until the complete adaptation to the news of abnormality, as well as the time spent in each one of them and the ability to reach the final phase or not (Irvin, Kennel, & Klaus, 1992). Therefore, there are the dichotomous categories 'Lack of hope' and 'Hopeful' at prenatal care, and the categories 'Concerning' and 'Relief' in the period at birth, representing the maternal individuality in accepting the diagnosis.

For Hiluey (2000), parents can idealize much worse conditions about the malformation detected during prenatal care than that detected after birth when they really meet the anomaly. Thus, the category 'Relief' presents in all moments analyzed in this work, represents the understanding of the child's condition. The lack of information and knowledge about the various malformations can exacerbate fears and anxieties alleviated after the adaptation period. This question is further explored in the section 'How have you found comfort?'

Some quotes taken in full from the interviews can exemplify:

I am relieved to see that he is fine now, I was afraid that he would not survive to delivery.

It is a sense of relief to see that she is responding well to medications and that although it is not the life I envisioned, she will be a happy and much-loved child.

The 'Guilt' category, present in the early infancy period, gives parents the responsibility of having generated a malformed child. Santos (2005) highlights the possibility of a malformed child remembering what is deficient in the maternal history, what was lacking, instead of representing a chance for reparation, as in a normal situation.

'Surprise', a category present at birth, was reported only by one mother due to the scientific community's desire to research children with rare malformations. This feeling was made explicit by the following sentence, taken in its entirety:

I felt in a movie, my son was an 'avatar'; everyone wants to research on him.

Search for comfort

Table 5 presents the response categories for the question 'How have you found comfort?'

Table 5. Response categories for the question, 'How have you found comfort?'

| Prenatal | At birth | Early Childhood |
|----------------|----------------|----------------------|
| Faith | Faith | Faith |
| Family | Family | Family |
| Special School | Special School | Special School |
| Doctor | Own Child | Own Child |
| Prognosis | Other mothers | Psychologist |
| Friends | Treatment | Did not find comfort |

Source: The authors.

To face, overcome and adapt to this new situation, parents use different coping strategies, depending on their individuality and context. Physical and psychological circumstances, such as physical and moral health, ideological beliefs, previous coping experiences, marital relationships, family characteristics, social contacts and economic situations, make up the personal coping resources (Vicente et al., 2016).

The two most listed categories repeated in the three different periods of diagnosis were faith and family. Having Faith in God or practicing any spirituality - related or not to a specific religion - can associate the occurrence of the malformation and the child's future with divine intervention. Mothers see the context as a divine purpose, facilitating the acceptance of the context. The focus on religious practices, in this case, indicates the existence of ideas permeated by feelings of hope and faith, as a way of dealing with the stressful situation (Gimenes, 1997), as observed in the report:

God can work miracles.

Usually, family members are the first to whom the mother confides about the malformation and, consequently, they are the first to help her overcome the difficult moment. The husband and mother are the closest family members and are remembered as comfort. The absence of the child's father is a factor that makes it difficult for the baby's mother to resolve adversities.

The doctor was a category for mothers diagnosed during the prenatal care, while the psychologist appears at early infancy. Health professionals help the family find solutions and weaknesses and needs, helping manage the context (Cunha, Pereira Junior, Caldeira, & Carneiro, 2016). In the case of prenatal care, the doctor is the one who gives the news to the mother and accompanies her until the day of delivery. A good doctor-patient relationship, characterized by the professional's ability to communicate the baby's condition, is decisive in maternal emotional overcoming. It is noteworthy the psychologist's importance to deal with the mourning over the loss of the perfect baby. Benzaquen (2002), in a work developed at the Serviço de Medicina Fetal do Hospital das Clínicas da UNESP (Fetal Medicine Service of UNESP Clinic Hospital), in Botucatu (a city in the state of São Paulo), with 42 pregnant women, with different malformations and with different levels of severity, observed the need for psychological support. According to the author, in the clinical monitoring of pregnant women, it is necessary to create a space that allows the expression of everyday thoughts and feelings in women with this diagnosis, such as intense sadness, guilt, anxiety, fear, avoidance, intrusive thoughts, among others. The presence of a Psychologist in the health team contributes to a welcoming, listening and preparing mothers to face the new situation. The support that accompanied the pregnancy and the first days after delivery proved to be

of great importance for the mothers' emotional adjustment and reestablishing the baby's bond.

Therefore, it is inferred how fundamental is the need for multi-professional assistance to children with congenital malformations, who has, in addition to technical and scientific training, competence, sensitivity and discernment for correct intervention in the biopsychosocial and spiritual context of the child and their relatives. (Santos et al., 2011).

The parents' initial responses and the amount of attachment to the child depend, in part, on the type of malformation, whether it is visible, the possibility of correction, the damaged functions in the central nervous system or the genitalia, whether it is familiar and whether it is incompatible with life. These characteristics are essential to elucidate over time the problems they will have to face (Sloper & Turner, 1993). The malformation's favorable prognosis also appeared as a comfort category for mothers with diagnosis during prenatal care, and treatment emerged as a category at birth. A good prognosis of the anomaly and its treatment fills parents with hope during prenatal and birth periods, due to a greater chance of the child recovering from the disease and even leading a normal life. Even if he is not as idealized, his own son, a beloved child, ends up transmitting strength to the mother and appears as a category at early infancy and birth.

However, in the face of an unfavorable prognosis - for example, when malformations are incompatible with life or those that cause severe sequelae - some mothers said they did not find comfort (category seen at early infancy diagnosis) and prefer 'to live one day at a time', without creating expectations for the child's future.

As for comfort and the search for support strategy, empathy is made explicit by the categories 'Other mothers' when the diagnosis is given at birth and 'Friends' during prenatal care. Although mothers do not yet have contact with special schools during prenatal and at birth, and as some interviews were conducted years after the birth of their child, institutions are mentioned in the three diagnostic periods. These institutions teach mothers to face their child's difficulties and help to contact other mothers and children with similar experiences. For emotional overcoming, the mother must not isolate herself and maintain an active social network, seeking support from those she trusts most. She must avoid to be centered only on that difficulty and finds other ways besides depression and isolation (Antunes & Patrocínio, 2007).

Final considerations

According to the period in which the news of a congenital malformation was given, it afflicts the mother's emotional state in several ways. The categories discussed in this work reiterate the fact that mothers go through psychological mourning - each differently, for variable recovery time and using different coping methods for this challenging situation according to the periods of diagnosis (at prenatal, at birth and early infancy).

The earlier the diagnosis of congenital malformation, the more time the couple has to seek information, understand the child's situation, accept the natural and expected feelings in the face of this condition, and better deal with the problem. Even so, categories such as sadness, surprise and despair were repeated in all periods analyzed in the survey. This shows the heterogeneity of family strategies to face adversity, varying according to the elapsed time and family structure. The final phase of psychological mourning and adaptation to the reality of having a child with the fetal anomaly is revealed in the 'Relief' category for the mother's current feeling that appears in all periods of diagnosis. The information obtained in this work contributes to psychological monitoring programs that aim to welcome, favor the

understanding and acceptance of the child with a congenital malformation, as well as instrumentalize the family to face the new condition. Besides, it alerts professionals to the importance of the scientific, emotional and ethical aspects of diagnosing fetal malformation to assist them better.

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