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Maternal perception in terms of newborns with congenital malformations: a descriptive study

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ABSTRACT

Aim: To identify maternal perception in terms of newborns with a diagnosis of congenital malformation, hospitalized in the intensive care unit. **Method:** This is a descriptive, cross-sectional study using a qualitative approach, performed in an intensive care unit. The sample was composed of mothers of newborns hospitalized for congenital malformation. We used a semi-structured interview as a data collection instrument. The interviews were recorded, transcribed and analysed by means of content analysis. **Results:** It was observed that mothers require a more humane *caring* approach at the time of disclosure, since this is a negative experience in the family environment. Three analytical categories emerged: the moment of disclosure of the diagnosis; maternal language regarding the diagnosis; and the professional approach at diagnosis. **Conclusion:** Professionals have great difficulty in communicating the diagnosis, and mothers have difficulties in handling the situation.

Descriptors: Neonatal Nursing; Congenital Abnormalities; Infant Newborn.

INTRODUCTION

Congenital anomalies are morphological deformities that are present at birth. Studies show that approximately 3% of newborns (NB) have a major abnormality, defined as a cosmetic or functional defect. This kind of disease is the most common cause of mortality in the first year of life and contributes significantly to morbidity and mortality during the early years of life. They occur due to various errors in morphogenesis and are set in malformations, breakages, deformation, sequence and syndrome^(1,2).

A child with a congenital anomaly represents a huge emotional burden. Most women are not prepared to face this challenge. With the advancement of paediatric medicine, the number of infants who survive with malformation after birth is increasing. A malformed child brings negative feelings about the idealization of the perfect baby birth for the couple and for the family, as the child is the self-image of the parents^(3,4).

The recognition of malfunction at the time of diagnosis leads to adverse reactions in parents with respect to this news, and its variability; for example, due to the manner in which the diagnosis is approached⁽⁵⁾. The diagnosis of congenital malformations in newborns has a significant impact on parents, especially the mother, since this news causes a particularly challenging and distressing period, with possible implications for their emotional condition^(6,1).

Given the above, it is important to identify the perceptions of mothers in terms of the revelation of a diagnosis of congenital malformation in a NB, in order to take into account their concerns and reactions after receiving the diagnosis. Therefore, our goal is to identify maternal perception in terms of the infant hospitalized with congenital malformation in the intensive care unit (ICU).

METHOD

Article of the Scientific Initiation Program - PROIC/FASI/FUNORTE entitled "Maternal perceptions in terms of the newborn diagnosed with congenital malformation hospitalized in ICU" presented to the Department of Education and Research, Faculty of Health Ibituruna (FASI) and United Colleges of the North of Minas Gerais (FUNORTE). Montes Claros, MG, Brazil. 2013.

It is a descriptive and cross-sectional study, using a qualitative approach, performed at the neonatal ICU at the University Hospital Clemente Faria (HUCF) in the municipality of Montes Claros, Minas Gerais.

The HUCF has 171 beds and offers another 10 that belong to the Inpatient Services in the Household (ISH). It has a Neonatal and Paediatric ICU, an Intensive Care Unit (ICU) for Adults, and a 24 hours Emergency Room (ER). It is a unique and genuinely public service offered in Montes Claros, and in a vast geographic region of the state; it tends the public exclusively through the Unified Health System (UHS).

The study sample was made by saturation of the statements and was held during the period from November 2013 to April 2014. The study involved nine mothers of NBs with congenital malformation who were hospitalized in the neonatal ICU and who agreed to participate in the study by signing the Informed Consent Form (ICF). The following inclusion criteria were adopted for study participation: mothers of newborns with congenital malformation who received medical information about the diagnosis, and mothers whose newborns were have no option but to stay in the NICU.

The instruments used for data collection were a semi-structured interview and a tape recorder. The testimony of the participants were recorded and later transcribed. The interview featured two guiding questions: *What is the*

mother's reaction when she receives the diagnosis of congenital malformation of her baby? and What is the maternal perception in terms of having her son remain in the NICU with this diagnosis?

Data analysis was done through Content Analysis, then three categories were formed for the study: "The moment of disclosure of the diagnosis"; "Maternal language in terms of the diagnosis"; and "The approach of the professional at the moment of diagnosis." The interviewed mothers were identified by the names of flowers in order to maintain the confidentiality and anonymity of the participants.

After categorization, we conducted a comparison of the data with the scientific literature. For this, we searched for scientific articles by means of a number of databases: Scientific Electronic Library Online (SciELO), Latin American and Caribbean Health Sciences Literature (LILACS), Regional Library of Medicine (BIREME) and Medical Literature Analysis and Retrieval System Online (MEDLINE).

The study followed the ethical principles established by Resolution No. 466/2012 of the National Health Council (NHC), which regulates research involving human subjects. The research project was assessed and approved by the Research Ethics Committee of the United Colleges of the North of Minas Gerais (CEP FUNORTE), under consubstantiated opinion 418,188/2013.

RESULTS

The moment of diagnostic disclosure

Although some birth defects are diagnosed at birth, most of these are detected prenatally. The parents go through this situation unexpectedly, experiencing a new challenge: on the one hand, the loss of a perfect and healthy baby, on the other, the birth of a child with distinct characteristics.

I was there on the delivery table; they were stitching me and the paediatrician came and spoke to me in a gentle way, you know? He said that my baby was born with a closed anus, so he would have to do surgery; he said it's very difficult to do a surgery like this. On the other day he managed to do the surgery, then he told me about the malformation in the baby's fingers, but I [...]. (Sunflower)

[...] On the same day I gave birth to the baby, I was lying in bed, waiting for them to bring him to me. Then I thought there was something strange, because it was taking them a long time to bring him. Only after did they tell me that he had a problem in the oesophagus, so they had to come to Montes Claros to do the surgery [...]. It was my mother in law who told me [...] that they did not want to tell me, because I had just given birth to him [...]. I was crying in pain, then she told me. Then it was too much, everyone was there for me; the nurses and the doctors gave me support. (Rose)

Maternal language concerning the diagnosis

Words expressing negative emotions and are usually attached to something bad, "dark spot", "malformation", "problem", "very serious", "dangerous". The expressions used by mothers bring a perception that is always connected to a negative idea and bad emotions. The negativity of these phrases can mean greater difficulty in accepting the situation. The very word "malformation" already carries this negative idea; the child who is described as "malformed" is then

considered the one who is not perfect and, thus, is no longer the ideal expected child.

They said it was normal, then my mom said that there was a risk he would be born with heart problems and in fact he was born with a heart problem. (Jasmine)

As he had a very serious problem [...] he had a major complication [...]. (Violet)

He discovered that she had only one kidney, but this fact had not yet been confirmed, then he thought she had both, but in the place of one kidney there was only a dark spot. But this spot was only the bowel, so there was only one kidney. (Camellia)

It is possible to perceive that mothers do not clearly describe the disease that their children really have. We noted in their speeches that they are aware of a problem, but do not understand the pathology.

Then I thought there was something strange, because it was taking them a long time to bring him. Only later did they tell me that he had a problem in the oesophagus, so they had to come to Montes Claros to do the surgery [...]. (Rosa)

The doctor said that he will bleed a little, just a little, but it is normal. Over the next fifteen days, he will bleed a little, but that is normal. He's very strong, very strong indeed. (Hydrangea)

He has two heart murmurs, so when he breathes the heart pumps water

and blood to his lungs, then he suffers changes in the liver [...]. (Azalea)

Professional approach at diagnosis

Because this is sensitive information, it is clear that mothers require a more specific approach at the time of disclosure, considering that this experience directly affects their personal maternity plan.

Professional behaviours that could be considered appropriate and inappropriate were reported. The mothers described the behaviours and attitudes of professionals who helped them in terms of accepting and dealing with the problem, as well as others who did not present the proper training to conduct these cases.

Wow! Every day the doctor said something different. There was a doctor, for example, with whom I got really upset. She said that there was no solution for my son. As he was in a very serious condition, she told me to prepare myself [...]. (Violet)

I was there on the delivery table; they were stitching me and the paediatrician came and spoke to me in a gentle way, you know? He said that my baby was born with a closed anus, so he would have to do surgery. (Girassol)

The moment when the diagnosis occurs influences maternal perception in terms of the degree of control and the preparedness to deal with the events surrounding the diagnosis of the baby. It is found that this experience is complex and very painful, especially when the professional who reveals the diagnosis behaves with contempt and a lack of preparation, and addresses the mother in an inappropriate manner.

[...] But on the day I underwent the ultrasound exam, the doctor here in Montes Claros, Dr. G., said that the heart of the baby was very advanced. Then I got there and talked to the doctors P. and they said that it was normal [...]. (Jasmine)

The doctor told me she was alright, everything was normal. I did not know anything; only when she was born did the doctor tell me. It was another doctor who attended the birth, it was he who gave me the news, but I had no idea about it. (Tulipa)

DISCUSSION

Receiving a diagnosis of congenital malformation has important implications for the emotional state of the parents and interferes directly in the post-pregnancy maternal experience⁽⁶⁾. The impact of the diagnosis for parents, especially for the mother, needs to be understood. The emotional, socioeconomic and cultural conditions of parents and family members should be considered, as the disease emerges from this context, and it is with this social-family structure that they will respond to the situation of the disease^(7,4).

It is common to construct an ideal child centred on the birth of a physically and mentally healthy baby; to develop images, dreams and hopes around the imagined "being", while, paradoxically, you are haunted by the risk of malformation throughout the gestational period^(7,4).

For mothers, in general, the time to see their child for the first time is taken by positive emotions, they do not expect their child to suffer from problems such as malformation. The moment when a diagnosis reporting this type of anomaly is disclosed is a great surprise for them⁽²⁾.

The experience of knowing that the child has a serious illness generates suffering, doubts and the immediate search for meaning in an attempt to understand this situation. This experience can be often confusing and exhausting for both the parents and their families^(7,8).

Thus, the professionals involved should communicate this information in an appropriate manner, with clear and easy language so parents can easily understand, thus providing conditions for the clarification of doubts⁽⁹⁾.

Mothers complain about the way the diagnosis is communicated, thus justifying feelings of anxiety, frustration and fear when hearing the news. This shows that the health professionals do not have the proper psychological preparation to give the diagnosis. This is because their own feelings emerge and the medical staff end up trying to ease the situation by giving false hopes, or they become extremely realistic and pessimistic about the prognosis of the child^(10,8).

Thus, uncovering what really happens during assistance provided to pregnant women or mothers in this context is not a simple task. A major difficulty is due to the lack of discussions regarding the theme of malformation among health teams, and among the mothers of babies with anomalies. It is believed that women and their families have many doubts, fears and uncertainties related to the future of the malformed baby, and the whole family, when they experience this situation. At this moment you need to feel cared for, respected, supported and assisted, and this role should be taken by health professionals at every stage of care, whether in prenatal, child-birth, or in the postpartum period^(10,11).

CONCLUSION

The study showed that the feelings experienced by mothers are very particular for several

reasons, such as the way professionals communicate the diagnosis and the place where mothers receive the news, since these generally interfere directly in the mothers' reaction regarding the situation. It is clearly noticed that mothers express identical feelings at the moment they become aware of malformation in the expected child. A critical moment is when the professional reports the presence of a problem. This is because the discovery, in terms of the malformation of the baby, produces a crisis and denial of expectations, generating the need to adapt the idealized infant into the real child, a process that takes time and occurs in a controversial manner by the mother and family throughout the course of pregnancy.

It is noted that mothers require a more specific approach when the diagnosis is disclosed (since it is sensitive information), and professionals have great difficulty in communicating the diagnosis to mothers in this situation.

We highlight the importance of the approach and preparation of professionals when a diagnosis of malformation is communicated in order to minimize the suffering of mothers. Specialized care is essential for these families, not only at the time of diagnosis, but also in the child's early days with its parents, in order they can develop a healthy relationship and reduce the triggering of unexpected feelings in mothers in both the postnatal and postpartum periods.

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