NEWBORNS WITH GASTROSCHISIS: ORAL HISTORY OF MOTHERS IN THE NEONATAL INTENSIVE THERAPY UNIT

ABSTRACT
Objective: to approach the perception of mothers whose newborns present a diagnosis of severe gastroschisis. Method: qualitative study using thematic oral history, performed in a public hospital with six mothers. The medical records of the NB and semi-structured interviews and field diaries were used as methods of data collection. Analysis was performed using the interactive model by Miles and Huberman. Results: The lack of knowledge regarding gastroschisis was evidenced in the discourses of the mothers; The lack of clarification, counseling and support for the family; The suffering due to experiencing the therapeutic process and returning home without their child. The subject professional support and overcoming the problem and the formation of the maternal bond was also revealed in the results. Conclusion: it was evidenced that having a NB with gastroschisis is a challenging reality and it involves experiencing mixed feelings and emotions, therefore requiring psychoemotional support. Descriptors: Newborn; Gastroschisis; Mother-Child Relations; Neonatal Intensive Care Unit.

RESUMO
Objetivo: abordar a percepção de mães cujos recém-nascidos apresentam diagnóstico de gastrosquisse de grande porte. Método: estudo qualitativo do tipo história oral temática, realizado em um hospital público, com seis mães. Utilizou-se para coleta das informações o prontuário do RN, a entrevista semiestruturada e o diário de campo. Para análise procedeu-se com o modelo interativo sugerido por Miles e Huberman. Resultados: a partir dos discursos das mães evidenciou-se o desconhecimento acerca da gastrosquisse; a falta de esclarecimento, aconselhamento e apoio à família; sofrimento em vivenciar o processo terapêutico e voltar para casa sem seu filho; foi revelado também o apoio profissional para a superação do problema e a formação do vínculo materno. Conclusão: evidenciou-se que ter RN com gastrosquisse é desafiador, é vivenciar uma ambivalência de sentimentos necessitando, portanto de apoio e suporte psicoemocional. Descriptores: Recém-Nascido; Gastrosquisse; Relações Mãe-Filho; Unidade de Terapia Intensiva Neonatal.

Original Article

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INTRODUCTION

The experience of having a child is the beginning of an important moment in the family life cycle especially for the mother - a moment of great celebration and hope, filled with ideas of how this new being will be part of the family, however, the diagnosis of some malformation in the baby, such as gastroschisis, significantly affects the ideal that the family had, which can provoke diverse psychoemotional reactions. The baby is born but different from what was imagined, a newborn (NB) with gastroschisis: 1 a rare congenital defect of the anterior abdominal wall.

A challenge that threatens the desired ideal - a healthy, strong, perfect baby, but the NB has an abdominal “hole” and its intestines are exposed 5,3 - a defect at the base of the umbilical pedicle, which causes the abdominal viscera of the newborn to be exposed (RN).2,4 This abdominal opening, a type of hernia, located to the right of the umbilical cord insertion, results in the evisceration of organs of the abdominal cavity, which, in the uterus, float freely in the amniotic fluid, and may cause inflammation.

Studies show that the incidence of gastroschisis has increased worldwide. According to data from the Latin American Collaborative Congenital Malformations Study (ECLAMC) the prevalence of gastroschisis in South America is 2.9 / 10,000 live births.5 Current data show that the incidence of gastroschisis ranges from 1-2 to 4-5 per 10,000 of live births.6

Its etiology is multifactorial and includes different maternal factors, including: mothers under 20 years of age; nutritional deficiency; smoking or exposure to tobacco smoke; use of aspirin in the first trimester of pregnancy, and high-risk pregnancies such as those complicated by infections; drug abuse or any other factor that contributes to the production of low birth weight. Low weight is directly related to intrauterine growth retardation, which influences the increase in the incidence of gastroschisis.7,4

Gastroschisis may also occur as an isolated defect or association with other gastrointestinal abnormalities.6 These anomalies are probably secondary to prenatal intestinal damage and are indicative of poorer prognosis.9 Often gastroschisis can be diagnosed by ultrasonography or by analysis of the amniotic fluid.4

These newborns require immediate surgical correction at birth - to minimize abdominal fluid losses, infections and prevent damage to the exposed viscera.2 with the aim to place the viscera into the cavity and close the abdominal wall. The postoperative period is associated with long periods of hospitalization, and represents a significant morbidity, mainly related to the delay in intestinal functioning.4,10,11 The mortality rate is 3.6% among newborns who have a complex gastroschisis,12 and is the third leading cause of death in a Neonatal Intensive Care Unit (NICU) in Spanish hospitals.7

Experiencing the hospitalization of a newborn with gastroschisis is challenging for mothers and their families, as they are constantly confronted with conflicting feelings and emotions, and each day they face the baby’s improvements and setbacks. Therefore, health professionals must give psychoemotional support to the family during each stage of the therapeutic process is necessary.

The nurse plays a fundamental role during the diagnosis and treatment of gastroschisis, as the nurse is responsible for the direct assistance to the newborn, and preparing the parents and relatives for the care and the stages that they will experience. It is up to the nurse to inform the family that this is a long hospitalization process with an average duration of 35 days, with a high probability of newborns developing infectious sepsis, and thus explaining to them about the results of the studies that approximately one third of the newborns may develop this type of life-threatening complication.13

In this context, the family also becomes a subject of care in the NICU, as the idea of the hoped-for-newborn NB is symbolically built in the family imaginary as the family dreams of a perfect baby and are shocked when they discover that their child has a severe abdominal defect. Thus, care should be provided not only with opportunities to express yourself, but with the possibility of feeling cared for by together with their child with gastroschisis. Complex care with life support equipment. A completely different situation from what was idealized by mothers and relatives.

From this point of view, understanding the reality of mothers who go through this experience, is a foundation for the praxis of thinking-reacting in neonatology, in that the close relationship promotes an understanding of the diverse reality, motivations, feelings of families.

From this perspective, the present study aims to understand the perception of mothers who had newborns diagnosed with gastroschisis and admitted to a NICU; to verify
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how the news of having an RN with gastroschisis was announced; and to describe the difficulties and/or acceptance the mother had with the diagnosis.

METHOD

Qualitative research using thematic oral history. The qualitative method allowed a closer approach, deepening of the facts, moving towards the universe of meanings.14 Thematic oral history consists of snippet from a life story, about a temporal period, a subject or subject of the interviewee, aiming to understand their experience, or that part of their life exclusively linked15-6 to gastroschisis.

The research location was a NICU of a public hospital, located in the capital of Bahia, in a reference hospital for neonatal surgeries. The selection of the subjects occurred between June 2011 and October 2012, during resident nursing specialization training in neonatal nursing. The sample type was intentional and consisted of six mothers who met the inclusion criteria: having a newborn with severe gastroschisis admitted to the NICU; have accompanied the newborn from the period of admission to hospital discharge; accept to participate in the research; and sign the free and informed consent form. The exclusion criteria included: not being emotional stable to tell their story and present difficulties with verbal communication. The study respected Resolution 422/2012 of the National Health Council, and was approved by the Committee of Ethics and Research (CEP) of the General Hospital Roberto Santos, under protocol number 003.

Data was collected from the following: the medical records of the NB to search for diagnostic data, behaviors, length of hospitalization and care performed, for inclusion in the study; the semi-structured interview, these were done individually in the NICU, and recorded in a digital recorder. After recording they were transcribed in full and identified with the nomenclature ‘Mother’ followed by the number according to the order of the interviews. The mothers statements were maintained in the way there recorded, colloquial, without orthographic or grammatical correction.

A field diary was used as another resource, in which impressions and observations of non-verbal communication were recorded, therefore using recent memory exercises.

The analysis of oral history reports consisted of content analysis in a dynamic and cyclical17 process of comings and goings that involved three components of concurrent activities: reduction, presentation and interpretation/verification of the data.

The analysis began by defining the theme and the literature review which searched for extracting meanings through the unfolding of the phenomenon studied.

The data and categories were then presented and configured on a diagram, which resulted into a meticulous and overlapping procedure until the understanding of the subject was reached, obtaining the verification of the data in the elaboration of the conclusion of the study.

RESULTS AND DISCUSSION

The mean age of the mothers was 22.5 years; 04 declared themselves as brown and 02 as black 02; 03 were Catholic and 03 were evangelical; Schooling: 05 had completed secondary school and 01 did not graduated from secondary school; Of the 06 mothers only 02 lived in the city in which the NB was hospitalized in; there were 03 female newborns and 03 male newborns, all were the first-born and from the mother’s first pregnancy.

Five categories emerged from the analysis of the interviews which contained the empirical data of the mothers' statements: Discovering gastroschisis; Experiencing the hospitalization of the newborn with gastroschisis in the NICU; The empty nest and The appreciation of the professional team.

◆ Discovering the gastroschisis

Two subcategories emerged from this category: the discovery of the diagnosis and the first contact with the newborn. Two aspects were found in the subcategory of the discovery of the diagnosis: the discovery of the diagnosis during prenatal care and the discovery of the diagnosis in labor. In both cases, the mothers stated that they had experienced distressing situation which they had never experienced before.

The mother’s lack of knowledge regarding the diagnosis of gastroschisis; the lack of explanations, counseling and support for the family by health professionals; and the difficulty to get a beds in NICUs, among others can be observed in the statements:

[...] during the morphological ultrasound he [doctor] told me that he [son] had gastroschisis, he did not specify what it was [...] he said he had a malformation, a surgical problem, and that there were risks and because he was a newborn, there were even more serious, [...] when he [the doctor] spoke of malformation, I was worried about what my child would be like [...] Will he be able to walk, will he
be a special child, a dependent child. (Mother 1)

I discovered in the ultrasound at five months. It appeared in the morphological ultrasound, the gastroschisis […] the doctor told me, explained that it was a malformation of the fetus in which the abdomen did not close […] sometimes there is a ninety-nine percent risk of death, and sometimes there are cases that are ok […] I do the surgery and it’s all right, but even so I was very nervous, worried […] afraid, because it was my first child […] I never knew I had this […] nor did I ever see a child born like this. (Mother 2)

The emotional impact of the news regarding the malformation triggers a variety of reactions in the parents, becoming a difficult experience for all family members. This pregnancy has clinical, psychological, emotional, social and economic repercussions for the family. The family, and especially the mother, who experiences the pregnancy of a malformed child, needs multiprofessional support in order to clarify doubts, to give information about the pathology, how the therapeutic process occurs, and to offer a biopsychosocial support to the family that is in a state of vulnerability.

In a context of acute coping - of the desired child with gastroschisis, it is necessary to evaluate the educational and socioeconomic levels of the families, in order to adapt to their language and, in this way, to help them understand the information and orientations which the team will provide. Imagine a mother who follows her prenatal care correctly, perform several ultrasounds, expects a healthy child and at the time of delivery, with all the expectations of having a normal child, and then she receives the news that her child has a malformation.

[…] the doctor did not diagnosis the gastroschisis in prenatal ultrasonography […] when I went into labor and went to the hospital it was then that the doctor told me that my daughter had a problem and so I would have to have a cesarean […] When she was born the doctor said that my daughter had a problem in her belly […] that her intestines were outside of her body, but she did not say it was gastroschisis […] I was sad, I expected a healthy child and she was born with this problem […]. (Mother 4)

[…] I did ever ultrasound and it never showed up, the doctors said that everything was normal with my daughter […] when I went into labor, the doctor tried to stop the delivery because she was 35 weeks, but could not […] so I had the normal birth and then after I got the news about the gastroschisis […] it was a scare for me and the father, it was something I did not know about, did not know what to do, nor how to proceed, it was difficult […] there was no surgeon in the maternity hospital, so we had to wait for a vacancy in another maternity hospital […] I went into despair because I did not understand what gastroschisis was […] the doctor only explained that the organs formed on the outside […] after I left, I looked on the internet […]. (Mother 5)

The possibility of the diagnoses of gastroschisis in the prenatal period, either by ultrasound or by any other evidence, allows the pregnant woman to be referred to a special care center, where a cesarean section can be performed, having a surgical and neonatal team prepared to perform the reconstructive surgery.

The statements reveal the need for better professional performance in clarifying the diagnosis, as well as improving the care directed towards the family and that the health team promotes differentiated psychoemotional support to the mother. As when the pregnant woman is adequately assisted, it is possible to minimize the health problems of the newborn, providing quality care to the mother and the infant.

After experiencing moments of distress with the diagnosis comes, the postpartum period, the time to see the long-awaited child, and it is at this moment that the mothers are faced with their real child - different from the imagined. Feelings and sensations are varied and expressed at this moment as: fear, sadness, crying, suffering, shock, worry, doubt, nervousness, disgust, despair, weakness, fright, rejection, anguish, anxiety, denial, pain, insecurity and unfulfilled dream.

[…] the moment I had my child the nurse wrapped her up [daughter], I was thinking, my God, is my child? Then the doctor came and described to me that the child’s belly was open and that the intestines were on the outside […] at that moment I was anxious, wanting to see, but I was afraid […] when I saw her, I froze and cried a lot I was numb. I cannot describe to this day what I felt at that moment, I went home and remained numb I did not know what to think […]. (Mother 1)

After the normal birth, the doctor showed me […] the whole intestine outside is very ugly[…] I was scared when I saw it, even though I was expecting it, even though we as mothers, we get a fright when we see it […] we panic, we are afraid […] but it was very quick and I saw very little […] they brought him to the nursery […]. (Mother 2)

[…] when my child was born the doctor showed me the intestines out of the belly
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[… ] when I saw it I was scared, I was sad […] I had never heard of gastroschisis […] I was expecting a healthy child […] I asked God so much to have a healthy baby and she was born with this problem [Mother 4]

When mothers encounter this real baby, it arouses feelings of sadness, grief, disappointment, inferiority and revolt. An abrupt disturbance plagues her emotional balance. They go through a unique experience, permeated by crying, loneliness, feelings of helplessness and an eagerness to escape from the situation.23 This fact of having a baby who does not meet idealized characteristics, as well the doubts about their survival, can interfere in the parents’ relationship with the newborn, even if the parents are not fully conscious of this process.24

The mothers never imagined having a NB with gastroschisis and such discovery caused conflicting feelings, they are required to readjust to this new reality and experience having a NB in the NICU, as is described in the next category.

♦ Experiencing the hospitalization of the newborn with gastroschisis in the NICU

Entering a NICU is a painful and frightening moment for mothers, it awakens feelings of helplessness, incapacity and fear of an unknown environment, in the NICU makes this environment impersonal and stressful. Despite being aware of the resources that the NICU offers, what most impacts mothers is the contrast between the fragility of the child and the number of devices, wires and tubes that the NB is connected to.

The mother’s first contact with the newborn with gastroschisis impact her life, as her child is in an unknown environment, in the process of surgical recovery, presenting hemodynamic instabilities, with strange equipment that they have never seen or heard of before. This new reality experienced by the mothers highlights the need for constant vigilance and multiprofessional support which helps them to cope with this new situation, as it is a long journey with moments of joy and sorrow; the latter mainly due to the instability of the newborn’s health, a factor which complicates the bond between the parents and children, and can be seen as a recurring issue during the entire hospitalization period.

During this hospitalization process, confused and ambivalent feelings emerged, triggering a series of biopsychosocial changes in the mothers. However, living with their NB with gastroschisis at the NICU allowed them to be more familiar with the environment, thus they were able to identify the importance of that environment for the maintenance of the baby’s life. The daily coexistence with the baby, and seeing the improvement from the treatment caused the mothers to bond with their children which in turn helped them to deal with the experience.

[...] I felt like a mother the moment I saw that her opening her eyes […] at that moment I hoped that everything would work out […] we already feel that love
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[...] and wanting my daughter to come and stay close to me there in her house [...] (Mother 1)
[...] it’s horrible to leave the maternity ward and not be able to take your child home [...] I just cried home, I could not do anything else. (Mother 3)
It was horrible to come home without him [son], it was as if I had left a piece of me, something was missing [...]. (Mother 6)

The birth of a child represents a unique moment of great celebration and expectations for parents and their entire family. A welcoming environment is created with beliefs and values.27 When this child needs to be hospitalized, this family experiences difficult moments, because that environment that was prepared to receive the child seems to have been in vain; the uncertainty of the child’s prognosis influences the family’s ideal.

The dream of leaving the hospital with their child in their arms is broken when they child is hospitalized in the NICU. At that moment, the family experiences an anticlimax, with feelings that go from worry to hope, and excitement to discouragement. Thus, mothers who go home without their newborn experience a sense of emptiness and loss because their child is not with them, cannot be visited by everybody, and their clinical conditions do not allow them to perform maternal care.29

These experiences also echo among the mothers of this study, highlighting the sensitiveness, fragility of the mothers, but also their hope for the maternal ‘nest’ of the home to be warmed up by the warmth of their child’s body.

♦ Professional care

The mothers’ reports show that NICU health professionals demonstrated emotional support which made their stay during the period of hospitalization of their newborns easier. They described them as a partner in care, people they could trust to care for their child.

It is clear from their statements that they value the professionals and the role that they play in this phase of life. The confidence in the care provided by these professionals allowed the mother to feel more relaxed when they went home.

[...] the care that she [the daughter] had was excellent, I can only give thanks [...]. you feel more relaxed knowing that the people are caring for her, giving attention and everything that she needs [...] everybody who rooted for her and that everything would go right [...] the doctors, the nurses all gave her the care she needed. (Mother 1)
[...] that concern of always wanting to be with her, and when I had to leave, I left
knowing that the people treated her [daughter] well, that what she [daughter] needed was there, and all I could do was pray and really trust, that everything would turn out to be OK and that she was in the best place [...]. (Mother 3) [...] the professionals are great, I received a lot of support from them, from everyone. I have nothing to complain about, the staff, the doctors, the nurses, they are all great, because I trust in them that I could have more strength [...] they do not care because they are obliged to, but they care out of love, they give the greatest care, they love their profession (Mother 6)

The way these professionals showed themselves to be attentive caregivers made the mothers feel more confident and therefore valued the team. This data is also corroborated in another study with premature infants admitted to a NICU, in which the professionals were evaluated for the quality of their care, and were recognized for their humanized and reliable care.\(^{30}\) Parents valued the nursing care, reporting that babies were cared for with the utmost of care and delicacy and that the NICU team was caring, competent and calming.

Nurses are recognized as professionals who preserve the quality of care and who show affection to the NB. It is a sensitive expression of care in the form of support, security and closeness to the RN. This act of humanization is expressed through touches and meaningful words from the heart.\(^{29}\)

The daily activities at the NICU are carried out in a comprehensive manner, based on updated knowledge based on scientific principles and techniques. These are essential points in any area of practice, but more than that the nurse must be a sensitive and transpersonal professional as the newborns who are admitted to the NICU present an unstable and severe clinical picture and frequently require the intervention of the nursing team.\(^{30}\)

**CONCLUSION**

Experiencing the diagnosis of gastroschisis and the hospitalization of their child in a NICU was a negative experience for the mothers, considering the length of hospitalization that this pathology requires, the high mortality rate and the emotional exhaustion experienced by mothers and their families.

The disarticulation of healthcare networks for pregnant women is made evident in the discourses of the mothers, such lack of articulation is confirmed by the lack of early diagnosis; the occurrence of births in an institution without surgical resources and the occurrence of normal vaginal deliveries, among others.

The need for ongoing psychoemotional support for the mother and family was evidenced, starting from the moment of diagnosis and clarification regarding the pathology until the conclusive therapeutic process and discharge from the NICU. Another aspect highlighted was the appreciation and recognition of the care provided by health professionals in the NICU, showing that care is permeated by feelings of love, affection and dedication. However, there is a lack of psychoemotional support for professionals who work with severely ill newborns, these professionals witness the suffering of the newborns, mothers and their families, and as human beings they also need emotional support in order to work in highly stressful environment.

In a scientific context, it is necessary to highlight the need for further investments in research regarding care of the newborn with gastroschisis, especially in the field of nursing science. The scarcity of scientific publications on this subject supports the necessity for further research which seek to explore different ways to care for the NB, family and professional caregivers in the context of gastroschisis, especially as it is a serious problem that represents a high mortality rate in Brazil.

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