

Experience of mothers in the feeding care for children with gastroschisis in the light of Ramona Mercer

Vivência de mães no cuidado alimentar do filho com gastrosquise à luz de Ramona Mercer

Vivencia de madres en el cuidado de alimentación de su hijo con gastrosquisis a la luz de Ramona Mercer

ABSTRACT

Objective: to understand the maternal experience in the feeding care of the child with gastroschisis and discuss the nurses' assistance to these mothers according to Ramona Mercer's conceptions of the maternal role. **Methods:** qualitative study conducted in two intensive care units (neonatal and surgical) of a federal institution in Rio de Janeiro. Eleven mothers of newborns with gastroschisis who fed by mouth and tube were interviewed. The data were analyzed and interpreted in the light of Bardin and Ramona Mercer. Results: the statements showed difficulties in the construction of maternal identity, since feeding the child with gastroschisis is challenging due to clinical instability, however, nursing support was fundamental in this process. **Conclusion:** giving voice and including mothers in care makes them feel safe in the creation of the mother-child bond and establish strategies for the development of the maternal role, even in the face of the obstacles imposed by the malformation.

Keywords: Gastroschisis; Children; Intensive Care Units; Mothers; Feeding.

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RESUMO

Objetivo: compreender a vivência materna no cuidado alimentar do filho com gastrosquise e discutir a assistência do enfermeiro a essas mães segundo as concepções de Ramona Mercer sobre o papel maternal. **Métodos:** estudo qualitativo realizado em duas unidades de terapia intensiva (neonatal e cirúrgica) de uma instituição federal no Rio de Janeiro. Foram entrevistadas 11 mães de recém-nascidos com gastrosquise que se alimentavam por via oral e sonda. Os dados foram analisados e interpretados à luz de Bardin e Ramona Mercer. Resultados: as falas evidenciaram dificuldades na construção da identidade materna, visto que alimentar o filho com gastrosquise é desafiador devido à instabilidade clínica, porém, o apoio da enfermagem mostrou-se fundamental nesse processo. **Conclusão:** dar voz e incluir as mães no cuidado faz com que elas se sintam seguras na criação do vínculo mãe-filho e estabeleçam estratégias para o desenvolvimento do papel materno, mesmo diante dos obstáculos impostos pela malformação.

Descritores: Gastrosquise; Crianças; Unidades de Terapia Intensiva; Mães; Alimentação.

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RESUMEN

Objetivo: comprender la vivencia materna en el cuidado de la alimentación del hijo con gastrosquisis y discutir la asistencia de enfermería a estas madres bajo la perspectiva de Ramona Mercer sobre el papel materno. **Métodos:** estudio cualitativo, realizado en dos unidades de cuidados intensivos (neonatal y quirúrgica) de una institución federal en Río de Janeiro. Se entrevistaron a 11 madres de recién nacidos con gastrosquisis, que se alimentaban vía oral y por sonda. Para el análisis e interpretación de los datos se utilizó la perspectiva de Bardin y de Ramona Mercer. Resultados: los relatos apuntaron a dificultades en la construcción de la identidad materna, pues alimentar al hijo con gastrosquisis es un desafío debido a la inestabilidad clínica; sin embargo, el apoyo de la enfermería resultó ser fundamental en este proceso. **Conclusión:** dar voz e incluir a las madres en el cuidado las hace sentir seguras en la creación del vínculo madre-hijo y establece estrategias para el desarrollo del rol materno, incluso ante obstáculos impuestos por esta malformación.

Descriptores: Gastrosquisis; Niños; Unidades de Cuidados Intensivos; Madres; Alimentación.

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INTRODUCTION

Pregnancy is almost always a very significant event for a couple, who idealize a healthy baby and create images, dreams and hopes in relation to this new being that will arrive in the family^(1,2). When, contrary to what was imagined, a malformed child is born, there is a discontinuity of these dreams and family disruption accompanied by a great burden, since the child's condition will require parents to deal with demands quite different from those of a child without malformation⁽³⁾.

Among the malformations that a newborn may present, gastroschisis is an abnormality resulting from the externalization of the abdominal viscera that leads to herniation of the mesentery – usually 4 to 6 cm in diameter –, the intestinal loops, the stomach, the liver and/or the bladder to the right of the umbilical cord, due to the incomplete closure of side leaflets during the 6th week of pregnancy^(4,5). Its incidence is approximately 2.98 cases per 10,000 live births, and the diagnosis is made by performing a morphological ultrasound between the 18th and 22nd week of pregnancy. Studies affirm that the etiology of gastroschisis is multifactorial, involving young maternal age, low income, low educational level, use of analgesics (aspirin, ibuprofen and paracetamol), smoking and nutritional factors^(6,7).

Due to the specificity of the malformation, these newborns cannot, at first, be fed in the mother's breast and, therefore, the first nutrients are provided to them by parenteral route. However, as soon as their clinical condition allows raw milked human milk (RMHM) or pasteurized milked human milk (PMHM) become the diet of first choice and, in the absence of these, one opts for the semi-elementary formula⁽⁸⁾. In this context, some feeding techniques are used, among them, the cup and finger-feeding¹, methods in which, to facilitate the future acceptance of the breast, small amounts of milk (5 ml) are offered, which will

be increased slowly and gradually, according to the tolerability of the newborn. Thus, with the evolution of the volume of the diet, parenteral nutrition will be reduced until the full diet is reached⁽⁹⁾.

Thus, the beginning of enteral feeding goes through careful evaluation by the surgeon and the neonatologist who, together, examine whether the newborn is able to receive some type of diet. As the baby's clinical evolution occurs, the mother is encouraged to offer the mother's breast to her child with caution, with the support of a health professional⁽⁸⁾. It is, however, a period of intense changes, in which "becoming a mother" is a challenge, which directly impacts the construction of the necessary affective bond⁽¹⁰⁾. For this reason, the mother of the child with gastroschisis needs to be included in the care of her child as early as possible, and the nursing team should encourage this participation gradually, recognizing and valuing the woman as an integral part of the care process.

In this scenario, health professionals, especially nurses, play an essential role in stimulating the mother in the care of the baby, always respecting her time of acceptance in the face of the disease, in order to help establish the mother-infant affective bond and reduce the stress caused by hospitalization⁽¹¹⁾. For this, these professionals must provide guidance and attentive listening, in order to help her recognize her potentialities, as well as her weaknesses and needs, so that she takes care of her child in the best possible way^(10,12).

It is noteworthy that the maternal role is acquired during the process of interaction with the baby. And this phase is reached when the mother attaches herself to the child and feels internal harmony, confidence and competence in the tasks of care and watching it develop. It is the final stage in which the mother reaches her maternal identity⁽¹³⁾. Mercer describes that, at this stage, the woman experiences satisfaction, pleasure and reward for the experience

¹ The finger-feeding method, translated to Portuguese as "alimentação pelo dedo ou sonda-dedo", consists of a technique of stimulation and oral feeding⁽⁹⁾.

of interacting with her baby in the fulfillment of the usual tasks inherent to motherhood⁽¹⁴⁾.

Thus, when making an approximation between the development of the maternal role presented by Mercer and the maternal transition, regarding the feeding care of her child with gastroschisis, the need for the mother to be supported by health professionals for the acquisition of this role in a healthy way is reinforced⁽¹⁰⁾. In addition, it is understood that the maternal figure is fundamental in the care of the child in an intensive care unit (ICU), while her participation in these processes certainly influences the development of her own maternal role.

In view of this, the following guiding questions were outlined: What is the mother's experience in the feeding care of her child with gastroschisis? How does the mother participate in the care of feeding her child with gastroschisis still in the intensive care unit?

The following objectives were defined: to understand the maternal experience in the feeding care of the child with gastroschisis and to discuss the nurses' assistance to these mothers, according to Ramona Mercer's theory of the maternal role.

In order to know the state of the art of research on the theme of feeding newborns with gastroschisis, a search was carried out in the electronic collections of the Virtual Health Library (VHL) - PubMed, MEDLINE, Latin American and Caribbean Health Sciences Literature (LILACS), Bibliographic Database Specialized in the Nursing Area of Brazil (BDENF) and Coordination for the Improvement of Higher Education Personnel (CAPES) - which covered national and international productions developed by health professionals.

Inclusion criteria were online articles published in full, in Portuguese, Spanish and English. Publications found in more than one database, case studies, review studies and book chapters were excluded. The descriptors used in the search were: Breastfeeding, Gastroschisis, Newborn, Neonatal Intensive Care Units, Mothers, Food and Human Milk.

All studies obtained in the search were of a quantitative nature, focusing on the types of food offered to the newborn and its consequences on the child's clinic, which demonstrates the relevance of this study, which will deal with the experience of mothers with children with gastrochisis regarding the nutritional care of their babies in the ICU.

METHODS

This is an exploratory, descriptive study, with a qualitative approach, and carried out in a Neonatal Intensive Care Unit (NICU) and Surgical Neonatal Intensive Care Unit (SNICU) of a federal public institution in the city of Rio de Janeiro, RJ specializing in women's, children's and adolescents' health. Such units were chosen due to the high rate of hospitalizations of babies with gastroschisis, as they are reference units for the correction of this anomaly.

The research participants were 11 mothers who met the inclusion criteria: mothers of children with gastroschisis admitted to the NICU or SNICU and who were feeding their children orally (breast and/or cup) and tube at the time of the research. Mothers whose emotional and psychic conditions prevented them from verbalizing their experiences and whose children were being exclusively fed parenterally were excluded.

Data were collected between May and July 2017, through the semi-structured interview technique, with the following guiding question: "Tell me how it is feeding your child in this inpatient unit." The interviews were recorded in a Digital Player (MP3) and had mean duration of 20 minutes, which were transcribed immediately after their respective conclusions, in order to facilitate the organization of the researcher's ideas.

The interruption of data collection and the definition of the selected sample size occurred with theoretical saturation in the 11th interview. The saturation criterion determines the cessation of inclusion of new participants, as the data present, in the researcher's evaluation, repetition and that it is not important to continue

data collection⁽¹⁵⁾. Thus, the interviews were interrupted when it was found that there was no new element in the empirical material, the result of the interviews. It is noteworthy that the study was able to contemplate all mothers who were feeding their children in the units studied during the period in which the data were collected.

This research complied with the ethical recommendations of Resolution 466/2012⁽¹⁶⁾ of the National Health Council, and was approved by the Ethics Committee under Opinions number 2,031,017 and number 2,071,930.

The mothers were captured by reading the medical records, which contained data on newborns, the history of childbirth and the main behaviors adopted. In possession of this information, the principal investigator, after explaining to each mother the objectives of the research and the dynamics of data collection, invited them to participate in the research. All agreed to participate and signed the Informed Consent Form, which elucidated the measures taken to ensure the anonymity and confidentiality of the data obtained. The best day and time for the interview was scheduled, which took place in a reserved room in the teaching department of the institution. Participants were identified with the letter "M" for mother, followed by an Arabic number related to the order of occurrence of the interview: M1 to M11.

For the analysis of the results, the Bardin content analysis technique was used, so that the first stage was the transcription of the interviews, accompanied by exhaustive readings. Soon after, there was the exploration of the material, the raw data of the registration units (RU) were separated by colors, totaling 193 RU, which were transformed into 107 meaning units (MU) and aggregated into four categories. Finally, the results were interpreted⁽¹⁷⁾, which will be presented below.

As a theoretical foundation, Ramona Mercer's contributions on the theory of achievement of the maternal role⁽¹³⁾ were brought to corroborate the discussions of this study.

RESULTS

Category 1 – Difficulties experienced by mothers in the process of feeding their children with gastroschisis

In the process of feeding the child with gastroschisis, the mothers experienced different feeding techniques, among them; they highlighted the gastric tube as a hindrance to the success of breastfeeding. Participant M3 said: "He spent a long time using the tube through his nose to receive the milk and so he became lazy, he did not want to breastfeed." Still about this difficulty, M7 stated: "After using the probe, she could not breastfeed, and then they tried the bottle, tried several nozzles until she was able to accept a little better in a half-flat nozzle [orthodontic], she continued spitting, but less than before."

In addition to the initial embarrassments in feeding the child through the cup, the participants expressed the fear of offering the milk in this way. According to the participants: "The little cup I did not offer. In the cup, I'm afraid of doing something wrong, giving too fast and she ends up vomiting or choking, [afraid of] ending up hurting her and getting in the way of the improvement she's having." (M1); "But when I saw [offer the cup], it was very difficult for him to drink, he moved a lot, he was very impatient and spat everything out." (M6); "I didn't get to give the cup no, I had a whole way to give, I don't think I could. I didn't give the cup, I was afraid to drop all the milk and do something stupid." (M8)

The difficulty in breastfeeding also emerged in the maternal speeches: "Initially [breastfeeding] was a somewhat painful experience, I had never breastfed, and sometimes [the breast] gets painful." (M2); "My experience of feeding my son was a difficult and painful process. I wanted him to suck properly; I was nervous so that he could suckle from my breast soon." (M6)

Category 2 – Experiencing moments of ups and downs in the process of feeding the child with gastroschisis

In the interviews, some factors were observed that caused the mothers to question their babies' food maintenance, as in the following statements: "Today, I arrived and she drank 15 ml [diet in the cup]; but she threw it out the first time, they tried to give the rest, but she didn't accept it." (M1); "From the beginning, when she started the diet in the cup, after two days she vomited, after a week they tried again, then she vomited again; This happened about four times."(M5)

Some mothers reported that, given the non-acceptance of the diet by their children, health professionals sought alternatives to offer the diet to the newborn from a list of feeding techniques, as evidenced in the following statements: "At first, he started feeding in the cup with 5 ml, but as he was not accepting it right, he spat everything, they [physicians] chose to pass a probe in his mouth and then passed it to a probe in his nose [to offer the diet and, thus, he was able to feed himself]." (M2); "She started feeding in the cup with 5ml, then they increased to 10, 15, increased each day 5ml, according to her acceptance, reaching up to 40 ml in the cup." (M4); "When my daughter started to eat, it was in a small cup; the milk was increasing every day, from 5 to 5 ml. Then, so she wouldn't miss the milk time [because the newborn (NB) didn't accept the cup], the nurses started using the probe in her mouth and they gave her the milk; so she was fed for a few days."(M7)

Category 3 – Overcoming difficulties in the process of feeding the child with gastroschisis

Despite the initial barriers, mothers who receive support from the health professional during the process of feeding their children are able to carry out the different feeding modalities with total confidence and enthusiasm, contributing to the baby's recovery, as can be seen in the following statements: "Now, I am able to

do it alone [diet], I only take the probe with the nurse, I place the tip of the probe near the nipple of my breast and the other part inside the cup and it sucks my breast and the cup together [transport of milk]." (M3); "I am who give her the bottle; I let her sit well and put the bottle in her mouth [...], the nurses taught me to turn the bottle well so that air does not enter her belly and she becomes bloated." (M7)

Amid the difficulties, these mothers found strength to overcome the obstacles existing in the process of breastfeeding their children in an intensive care unit. The participants stated: "Very pleasurable and very good [breastfeeding], despite being painful, it was never something that could not be endured. It is a bearable pain and a very good feeling, I waited a lot for it, because he has already been hospitalized for 40 days and is only being breastfed for 5 days. So every contact with him is very important to me." (M2); "Now it is being good [the breastfeeding experience]." (M3)

Category 4 – Nurses' actions in the process of caring for the newborn and maternal embracement to achieve the maternal role

The support of the nursing team was pointed out by the mothers as fundamental in the process of caring for their children in the NICU, according to the participants: "I only took [the NB] because the nurse asked and insisted to put her on my lap, for her to improve, to feel that her mother is there, close to her." (M1); "The nurses are great, they give all necessary support in the care of my baby [...], in the Neonatal ICU, they [nursing staff] put those breastfeeding chairs, which have helped a lot to breastfeed."(M2); "The nurse taught me to offer the cup."(M4); "But even though I didn't breastfeed my baby [yet], I had a breastfeeding class here at the milk bank, the nurses taught me how to suck milk from my breast." (M5); "With the help of the nurses and the milk bank, I was able to breastfeed my son. They helped me by putting him on my breast; they said that he breastfeeding would increase my production [...].

When he sucked on my breast, together, they put a little probe for him to pull on my breast and cup at the same time.” (M6); “It was something participatory yes, the nurses include us a lot in the care.” (M7); “When I breastfed I asked the nurses to put him on my lap [...], when it was time for his breastfeeding, the nurses would help me and let me give my breast, and he would breastfeed properly.” (M8)

DISCUSSION

Gastroschisis is a pathology that demands attention with regard to the beginning of the feeding of the newborn, since the slow and progressive stages in the process of feeding the baby cause, in the mother, anguish, apprehension, feeling of impotence and uncertainties, since they can lead to future complications in the supply of the diet⁽¹⁸⁾. For this reason, although the mother cannot breastfeed immediately, her presence within the Neonatal ICU next to the child is paramount, since the professional team can guide and encourage her in the care of the baby, starting an attentive listening to help her understand the environment in which she is inserted and to identify her needs in the course of treatment⁽¹⁹⁾.

In view of the established prognosis, the mother, instead of breastfeeding the child, experiences different feeding techniques, among them, the use of the cup and the gastric tube. Maternal reports revealed that this process arouses concerns, as these are techniques that can delay the success of breastfeeding, since, according to the clinical picture, the newborn may present loss of nutrients and regression in tolerance to the diet^(20,11).

Some factors, such as the child's health status and complications in food evolution, possibly prevent the mother from developing an adequate maternal role, that is, her involvement in the entire health-disease process of the child has the potential to directly affect the baby's health status and her identity as a mother⁽¹⁴⁾.

Pain in the initial breastfeeding process was one of the difficulties mentioned by mothers and is related to the fact that the newborn goes days

without oral experimentation, compromising the suction function and causing an inadequate grip and causing moments of pain instead of pleasure⁽²¹⁾. For these reasons, it is necessary to encourage the performance of non-nutritive sucking, which is a method used to decrease the time of feeding probes and improve the neurological and motor stimuli of the newborn, favoring the receipt of breastfeeding⁽²²⁾.

According to Mercer, in the process of becoming a mother, when faced with unfavorable situations, such as discomfort caused by pain in breastfeeding, the woman experiences negative feelings that can result in early weaning and cause a distance from her baby⁽¹⁴⁾.

In the oral experimentation phase, it is verified that the newborn with gastroschisis goes through ups and downs regarding the progression of the diet. Some neonates present intolerance to the diet, manifested by abdominal distension, emesis, bilious gastric stasis and stop/decrease the elimination of gases and feces, and remain longer hospitalized⁽¹⁸⁾.

The clinical instability of the newborn imposes on the mother the daily interaction with the uncertainties of the prognosis. Feeding the baby requires differentiated care, as the tolerance of the gastrointestinal tract is small, so that it goes through evolutionary and retrograde moments in the feeding process. Such difficulties leave mothers tense and anxious about their children's recovery^(18,23).

It is noteworthy that the tensions generated by conflicting situations can impair the adoption of the maternal role, interfering in the bonding process with the child. Therefore, the health professionals need to be attentive to recognize these feelings and help mothers overcome them, which can contribute to the establishment of the maternal role⁽¹⁴⁾.

Faced with uncertainties in the process of feeding the infant, the multidisciplinary team has been improving techniques and seeking alternatives for a better adaptation to the feeding transition of this newborn⁽⁹⁾. Among them, the theory of achieving the maternal role allows

nurses to identify factors that may influence the process of becoming a mother, providing a basis for the elaboration of care plans and appropriate interventions to strengthen the maternal identity phase⁽²⁴⁾.

There are many obstacles faced by mothers in a NICU, however, they find strength and seek strategies to overcome the challenges in child care. With the support network created in the hospital environment, including the time they spend with their babies, mothers end up learning breastfeeding techniques, feel safe during the procedure⁽²⁵⁾ and realize that feeding their babies, regardless of form, is a pleasurable and rewarding moment, as they may notice that their children show signs of evolution with regard to the way they feed. In this context, mothers seek to participate more actively in the food care of their children, always counting on the support of the professionals⁽¹⁹⁾.

In this way, Mercer states that the mother feeling included in the care of her child increases the self-perception of maternal efficacy, considering that she sees herself as the provider of the relationship and care. The positive response of this meeting gives the mother an increase in self-esteem and favors the effective bonding of the mother and child binomial⁽²⁴⁾.

With regard to the role of nurses in the care of the baby, it was evident, through the statements of the research participants, that the mothers valued the support and associate the positive result with the humanized care provided by the health professionals, both in relation to the recovery of the child's health and the support for them to build the bond with the newborn within an intensive care unit. That is, it is shown that these facts are in line with studies that emphasize the importance of these professionals for women to feel safe and empowered in the care of their children, even in a hostile environment⁽²⁶⁾.

According to Mercer, nurses are paramount in the process of transition to motherhood, mediating conflicts and offering resources for the effective adoption of the maternal role⁽²⁴⁾.

The author also points out that nurses, by supporting mothers in the care/feeding process, provide mothers with knowledge and bonding with their children when they learn to take care of them, copying the behavior of specialists and following their guidelines⁽¹⁴⁾.

CONCLUSION

The present study aimed to understand the daily life and unveil the wishes of mothers in the food care of their children with gastroschisis admitted to an ICU. The interviews revealed an experience permeated by moments of fear, anguish and uncertainty, but also of great strength and confrontation.

Thus, giving voice to these mothers led to the understanding of how this experience took place and, in particular, how the food care of the hospitalized newborn was carried out, showing the factors involved in the experience of these women with motherhood. It was possible to notice that, faced with so many fears and limitations imposed by the malformation, the mothers yearned to assume their child care tasks, because, in the speech of each one, the ability to adapt to the situation emerged, by characterizing how pleasurable and rewarding was the opportunity to take care of the child even in a hostile environment, finding a new way to understand life and experience motherhood.

In this walk, it is of paramount importance that the systems that surround the support network of these women, whether the hospital unit or the family, meet their needs for emotional and physical care, in addition to encouraging them in the demands of care for the children, so that they can effectively overcome the adversities imposed by the malformation.

Nurses, with their essence of care and guidance, emphasize the importance of maternal presence for the recovery of newborns and help these mothers to reach all stages until the construction of the maternal identity, giving them all support and security in the acts of care.

As a limitation of the study, it is observed the fact that it was carried out in a single neonatal

hospital unit, which limits the generalization of the findings, since the data indicate a *deficit* in maternal protagonism, when considering the importance of maternal participation in the care of the child admitted to a neonatal intensive care unit. Studies are recommended in other hospital settings in order to expand knowledge on the subject.

The present study contributed to the construction of knowledge on the subject of children with congenital malformations, specifically children with gastroschisis, enabling the visibility of the food care performed by these mothers, with the support of nursing, within a unit full of technological apparatuses unknown to them.

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