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PERCEPTION AND ATTITUDE OF PARENTS TOWARDS NEWBORN PAIN IN NEONATAL UNIT

Percepção e atitude de pais diante da dor do filho recém-nascido internado em unidade neonatal

Percepción y actitud de los padres ante el dolor del niño recién nacido en unidad neonatal

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ABSTRACT

Objective: To understand the perception and attitude of parents of newborns admitted to a neonatal unit about their children's pain. **Methods:** Qualitative, exploratory research. Twenty semi-structured interviews were conducted with parents of newborn addressing the relationship between the health professionals and their children, and their approach to painful events. Content Analysis was performed with a thematic approach. **Results:** The parents perceived pain through their child's behavior and attributed painful procedures and prematurity as cause. Some non-painful procedures were listed as such, for example, tape removal. Mothers, compared to fathers, were more sensitive to pain identification. Regarding the attitude towards this, some mentioned caring, others, escape and some reported asking the professionals for help. **Conclusion:** Providing support to parents can make them feel safer about caring for their child, even in the face of pain. Thus, they can take an active stance towards the perception of pain in their newborns.

Descriptors: Pain, Pain perception, Father-child relations, Mother-child Relations, Intensive care units, Neonatal.

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RESUMO

Objetivo: Compreender a percepção e a atitude de pais e mães de recém-nascidos internados em Unidade Neonatal sobre a dor de seus filhos. **Método:** pesquisa qualitativa, exploratória. Realizou-se vinte entrevistas semiestruturadas com genitores de neonatos abordando a relação entre profissionais de saúde e seus filhos, e sua abordagem ante eventos dolorosos. Realizou-se Análise de Conteúdo na modalidade temática. **Resultados:** os genitores perceberam dor pelo comportamento do filho e atribuíram como causa, procedimentos dolorosos e prematuridade. Alguns procedimentos não dolorosos foram elencados como tal, como retirada de esparadrapo. Mães, comparadas aos pais, apresentaram-se mais sensíveis à identificação da dor. Quanto à atitude diante desta, alguns citaram cuidados, outros, fuga e alguns relataram pedir ajuda aos profissionais. **Conclusão:** oferecer suporte aos pais pode fazer com que se sintam mais seguros para o cuidado do filho, mesmo diante da dor. Assim, podem assumir postura ativa diante da percepção da dor em seus recém-nascidos.

Descritores: Dor, Percepção da dor, Relações pai-filho, Relações mãe-filho, Unidades de terapia intensiva neonatal.

RESUMEN

Objetivo: Comprender la percepción y actitud de los padres de recién nacidos ingresados en una unidad neonatal sobre el dolor de sus hijos. **Método:** investigación cualitativa, exploratoria. Se realizaron veinte entrevistas semiestructuradas con padres de recién nacidos para abordar la relación entre los profesionales de la salud y sus hijos, y su enfoque ante los eventos dolorosos. El análisis de contenido se realizó en la modalidad temática. **Resultados:** los padres percibieron el dolor debido al comportamiento de sus hijos y atribuyeron los procedimientos dolorosos y la prematuridad como causa. Algunos procedimientos no dolorosos se enumeraron como tales, como la extracción de cinta. Las madres, en comparación con los padres, eran más sensibles a la identificación del dolor. Con respecto a la actitud hacia esto, algunos mencionaron precauciones, otros, escaparon y algunos informaron que pidieron ayuda a los profesionales. **Conclusión:** brindar apoyo a los padres puede hacerlos sentir más seguros para cuidar a sus hijos, incluso ante el dolor. Por lo tanto, pueden adoptar una postura activa hacia la percepción del dolor en sus recién nacidos.

Descriptores: Dolor, Percepción del dolor, Relaciones padre-hijo, Relaciones madre-hijo, Unidades de cuidado intensivo neonatal.

INTRODUCTION

Newborns exposed to emotional stress situations tend to communicate more intensely.[1] Even preterm newborns emit non-verbal signals of communication such as body movements, facial expression, crying and vocal murmurs when not intubated.[2] These forms of communication can be recognized and used by parents, mothers and caregivers to identify pain, physiological needs, hunger and sleep, including in a hospital environment.[3]

Pain is a universal somatic experience that reflects a person's apprehension about a threat to their bodily or existential integrity.[4] In children, the response to this stimulus is conditioned by several factors, among them, the cognitive level, which will to modulate their response and perception.[5] Since neonates are non-verbal children, measuring pain is a challenge, so that physiological and behavioral indicators are used as substitutes for self-report. For this, professionals depend on the use of scales.[6]

Currently, there is an expressive number of pain scales for newborns, such as: Neonatal Facial Activity Coding System (NFCS); RN Pain Assessment Scale (NIPS); Neonatal Pain, Agitation and Sedation Scale (N-PASS); Premature Infant Pain Profile (PIPP); Score for Post-Operative Pain Assessment of Newborns (CRIES).[7] However, none of these forms of assessment includes the participation of fathers and mothers.[8] Their contribution in identifying and conducting their children's pain may be fundamental for more effective analgesic care.[9]

Thus, this research aimed to understand the perception and attitude of fathers and mothers of newborns hospitalized in a Neonatal Unit about their children's pain.

METHODS

Qualitative exploratory research. Held in a university hospital in a capital city of northeastern Brazil between May and June 2014. During the study period, the Neonatology Service had 40 beds. Fathers and / or mothers of babies admitted to the Neonatal Unit (UN) during the study period were included. The saturation criterion was used to define the sample.

Semi-structured interviews were carried out. The instruments were: structured questionnaire, with sociodemographic aspects and data from the medical record; and semi-structured interview script, with open questions.

For data collection, the invitation was made and, after acceptance, the interview was scheduled. At the meeting, the free and informed consent form (ICF) was read and signed, the questionnaire was filled out and the interview was conducted, which was recorded and later transcribed.

Content Analysis was used in the Thematic modality for data interpretation, following the pre-analysis, categorization and interpretation steps.[10]

Research approved in accordance with resolution 466/12 and its supplements from the National Health Council, CAEE 20776213.0.0000.5086. Seeking to ensure anonymity, the names have been replaced.

RESULTS AND DISCUSSION

Seven mothers, one father and six couples were interviewed, totaling 20 participants, involving 15 newborns (two were twins).

As for the mothers interviewed, the age ranged from 18 to 41 years, the majority referred to complete high school, Catholic religion, consensual union and a single child. The parents were aged between 26 and 39 years old, Catholics and Evangelicals, complete high school, predominance of consensual union with one to two children.

Of the 15 newborns, 14 were born at the study site, half were male, with a varied Apgar score, with the majority above five in the first minute. Gestational age (GA) and chronological age varied, respectively, from 24 to 36 weeks and from 8 days to 5 months and 3 days. Birth weight ranged from 680 to 2984g and current weight from 960 to 3360g. The main diagnoses were extreme prematurity, hyaline membrane disease and malformation.

With regard to conducts and procedures, deep venous access and mechanical pulmonary ventilation (MPV) were the most frequent. With regard to pain relief measures recorded in medical records, pharmacological measures were more frequent and, among non-pharmacological measures, the kangaroo position.

For the fathers and mothers interviewed, the children felt pain as a result of handling, procedures and even prematurity. They expressed pain due to crying or different behaviors. The findings are presented based on the perception of pain: "the pain exists" and the attitudes they assume when they perceive the pain: "I take care of it".

Perception of pain: pain exists

In most interviews, fathers and mothers claimed to perceive situations of pain when their children cried. Crying is one of the forms of language by which the baby communicates and expresses his pain.[2] However, crying can also indicate anger, discomfort and hunger.[11] Magnólia's account highlights this aspect of crying.

> *When it's crying hungry, I feed it. When you eat and don't stop crying, it's pain. (Magnolia, 27 years old)*

Facial expression was also recognized as one of the signs of pain. This is an important issue considering that many sick neonates, especially preterm infants, are unable to express their pain with crying, such as Margarida's newborn, born at 36 weeks.

> *You look at your baby and know that he is in pain. (Margarida, 18 years old)*

Newborns have specific facial expressions and indications of pain and it is up to the caregivers to distinguish these messages emitted, either by facial expressions or by attitudes such as "shaking the legs" and "pulling the hand".[12] In the interviews, this was evidenced in the speaks of Delfino:

> *It keeps stirring, twisting. That's when I realize he's in pain. (Delfino, 33 years old)*

Irritation and excessive limb movements can be related to pain. However, they can also be present in non-painful stimuli.[13]

The parents' perception went beyond the bodily messages sent by the newborn. With the prolongation of hospitalization, they also began to perceive physiological changes as an expression of pain, as in the speech of Lélia (child hospitalized for five months).

> *He's in pain because he turns purple... He's not saturating [well]. (Lélia, 22 years old)*

The incorporation, by mothers, of professional language represents an adaptation to this situation so different from that expected during pregnancy. After the birth of a full-term child, without complications, mothers develop care that involves breastfeeding, hygiene, among others, called by Winnicott as "primary maternal concern".[14] Given the birth of a child with problems and his hospitalization, this behavior is modified, and mothers develop concerns about aspects related to the disease and treatment, incorporating medical terms. This behavior is called "primary medical concern".[15]

When asked about what causes pain, the interviewees presented different perceptions, but for most, pain was associated with procedures performed during hospitalization, with an emphasis on puncture for venous access. In a study in which the babies' faces were photographed in various situations, including the heel puncture, their pain expression was evident.[16]

One couple, whose son, born at 34 weeks, had peripheral venous access and on mechanical lung ventilation, reported not knowing the reason for the pain. No pain relief measures were identified in this newborn's medical record.

> *I didn't realize why he is in pain. (Jasmine, 35 years old)*
> *The crying was because the puncture bothered me. Not because it hurt. (Narcissus, 35 years old)*

Fathers and mothers, even though they perceive pain, seek denial, a healthy way to behave in the face of an unexpected moment. Denial can act as a filter to understand the situation and develop a concrete plan in the face of pain. In addition, it would be unbearable for fathers and mothers of newborns to accept the daily pain their children are subject to.[13]

There are cases in which the pain may, in fact, be absent both due to the absence of painful stimuli and the care of the team.[13] However, in the case of Jasmim and Narciso's newborn, there were obvious reasons for the pain.

The parents reported that the frequency with which the attacks were performed influenced the pain

intensity. Anis, mother of a newborn with 24 weeks of GA said:

Sometimes it hurts because it takes one, two, three ... Several holes. (Anis, 37 years old)

In a recent systematic review, it was observed that in the first 15 days of life, newborns admitted to the NICU undergo 7.5 to 17.3 painful procedures a day.[17]

The performance of surgeries was another highlight. Many fathers and mothers have listed this procedure as a cause of pain. Most cited the immediate postoperative period as the most painful moment and in many medical records there was no prescription for analgesia.

In a study on painful procedures in the NICU, the use of analgesia in surgical recovery increased from 33% in 2001 to 89% in 2011. In contrast, more than 10% of neonates hospitalized in the four units analyzed in the survey, in 2011, did not receive any analgesia in the first three postoperative days.[18]

Alisson's speech drew attention to other painful stimuli.

The day I most saw her crying in pain was when she removed the tape. (Alisson, 27 years old)

The constant exposure of children to painful procedures during the hospitalization period increases their sensitivity to pain, causing non-painful stimuli to have repercussions on pain.[19]

On the other hand, the parents suggested adapting to pain in the face of constant exposure, as observed in the words of Hortência, a preterm mother born at 29 weeks.

I can't tell you how many times a day she had to do this to get used to this feeling of pain. (Hortência, 29 years old)

Despite the fact that children hospitalized in BU are subject to painful situations, such as: invasive procedures, separation of the child from the parents and chronic pain related to the clinical condition itself; beliefs that the newborns gets used to pain stimuli persist.[20] Fathers and mothers are attentive to pain in their newborns admitted to the UN, but the subjectivity inherent to each of them allows different perceptions, including denial.[16]

The importance attributed to sharps and to the immediate postoperative period is highlighted, which, as it turned out, has been neglected not only in our study.[20]

In some interviews, caregivers raised the possibility that prematurity made newborns unable to feel pain.

Because he is very premature, I cannot say whether he was in pain. (Anis, 37 years old)

The neurological response to pain is similar among preterm, full-term newborns and adults. In the twentieth week of gestation, the ascending nociceptive pathways acquire functionality and the newborns are able to feel pain.[21]

Sometimes, divergences of perception were identified between the couple. Florêncio, (father of a preterm baby) said: "I don't think he feels any pain. It's too small". However, for the mother, Amarilis, the son screamed in pain. Sometimes the contradiction was observed in the same interviewee. Lélia, 22 years old, said: "They are premature, they don't feel pain", but later she recognized that her son felt pain due to a fracture.

Some mothers of children who have undergone painful procedures, especially those of the first child, also reported that preterms did not feel pain. In one of these cases, the newborn was prescribed morphine.

In addition, mothers whose children had prolonged hospitalization (more than 20 days) and, therefore, greater contact with the baby and the team, demonstrated a lack of knowledge and difficulty in identifying the signals emitted by their children.

However, in another statement, the report indicated that prematurity and low weight could exacerbate the pain.

She has more pain than babies born at the right time. (Alisson, 27 years old)

Primiparity, gestational age at birth and length of hospital stay, influence mothers' perception of pain. These newborns are exposed to many painful stimuli, a fact that makes fathers and mothers underestimate many of the newborn's forms of communication, in addition it is necessary to look sharply to understand their signs.[11]

For the family, the birth of the child is capable of producing paradoxical feelings, ranging from joy at the birth of a child, to suffering, frustration and incompetence due to the anticipation of birth and the baby's fragility. This vulnerability brings the need for caregivers' perception of the proper management of baby care.[22]

Attitudes towards pain: I take care of it

Many interviewees reported crying and feeling helpless towards the child's pain perception, however, even in the Neonatal ICU environment, fathers and mothers recognized that they could actively act to relieve their child's pain. The most frequent report was the desire to touch and provide care, which translated into different forms: offering a lap, breastfeeding,

talking, singing, and holding the baby's hand.

Affection relieves [the pain]. (Perpetual, 33 years old)
I try to cuddle by running my hand. Then I breastfeed. The pain passes. (Anis, 37 years old)

The environment can inhibit the attitude of parents, who, depending on the number of children and age, may exhibit different behaviors. Mothers of first children or younger tend to passivity in the face of pain.[3]

Some fathers and most mothers reported that in the Kangaroo position, the newborns appeared calmer and more comfortable and that they felt less pain. Cosmos, a 39-year-old father, said: "When I put him on the kangaroo, he relieved". A study on the father's participation in the children's hospitalization showed that although the role of primary caregiver is that of the mother, the parents showed involvement and an active attitude.[23]

The Kangaroo Method is responsible for the integration between father, mother and newborn. It favors the bond and the sense of competence to take care of the children.[24] In the statements, the importance attributed to the Kangaroo Method was evident.

Skin-to-skin contact during a painful procedure reduces physiological and behavioral signs of pain. It is indicated that it be kept before, during and after the painful procedure,[25] as well as breast milk, which in addition to the nutritional and affective benefits for the baby, can also be a potent intervention for pain relief. Breastfeeding during puncture in neonatal screening ensures less autonomic activation and lower pain score.[26]

Thus, despite some differences found between father and mother, between younger and older, having more children or not, breast milk and the Kangaroo Method were listed as forms of care for fathers and mothers in relation to the children admitted to UN.

Some interviewees described escape attitudes, such as going out during the procedure. Others, reported not knowing how to act in the face of pain situations experienced by their children, like Alisson, 27 years old:

"Most of the time I lose focus when I perceive pain".

Another attitude found was to ask the nursing staff for help, especially when they felt powerless in the face of the situation experienced by their children. Like Perpétua, 33 years old, mother of a preterm newborn:

"I call the nurses. I trust what they tell me".

During hospitalization and in the eventual moments of the baby's pain, the health team assumed duties and responsibilities that demand skills for assessment, understanding and support for the child and his family.[27] A relationship of mutual dependence emerges, in which the parents need the knowledge professionals and, for the team, the presence of parents is essential to offer comfort to the newborn and even to assist in the dynamics of work.[28]

The precision of the care provided by the health team can awaken in parents the feeling of inability to help their child. Such barriers, between health staff and family members, must be broken so that fathers and mothers are included in the care of the newborn.[29]

A condition mentioned by the parents and that can contribute to this difficulty in taking action is the feeling of guilt for the baby's clinical condition and the consequent need for hospitalization and the procedures that cause pain.

We even blame ourselves. The baby was supposed to be guarded. But you're out and you have to be careful. (Amaryllis, 30 years old)

Feelings such as suffering, fear, stress, guilt or insecurity are common to newborn caregivers admitted to the UN and require listening, support and assistance. It is essential that parents are encouraged and oriented to participate in the recovery and development of the newborn, given the feeling of helplessness and distance in the face of hospitalization.[27]

A limitation of this research might be the fact that the interviews were conducted at the hospital. Although they were previously scheduled, and we had the availability of a reserved environment, it is possible that this has influenced some responses. Despite this, it is believed that with the interviews it was possible to achieve the research objectives, in addition to creating a space for listening and exchanging experiences that was beneficial to parents in this moment of fragility.

CONCLUSION

Contradictions were found in the statements of parents regarding the perception of pain. Some reported that because their children were born preterm, they feel less pain, probably reproducing knowledge that for a long time was disseminated by health professionals themselves. The main pain behaviors identified in newborns were crying, facial expression, body movements and physiological changes.

As for acting in the face of pain, although some fathers and mothers have shown active behavior in

order to resolve or seek help, most reported feelings of fear and escape behavior.

It is concluded that offering support to parents can make them feel safer by assuming an active posture in the face of the perception of pain in their newborns.

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