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THE EXPERIENCE OF THE MULTIPROFESSIONAL TEAM IN FRONT OF PALLIATIVE CARE IN A NEONATAL INTENSIVE CARE UNIT

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Abstract: The care given in the NICU will not only consist of intensive care, but also help the patients' families to make wise decisions regarding the end of life. This study aims to understand the experience of the multidisciplinary team facing palliative care in Neonatal Units. The approach was qualitative, carried out with NICU professionals, which used a semi-structured interview as a collection instrument. The results were analyzed using the Content Analysis method. Through the results, three thematic categories emerged: 'Working between life and death: Experiences in a NICU'; '' Palliative care: when death is certain, what to do?" and '' Palliation and the family.". Through the results shown, strategies can be developed to facilitate this process, with a focus on quality of life for the family, newborn and professional.

Keywords: Multiprofessional team, family, neonate, care, comfort.

INTRODUCTION

Advances in technology in the fields of medicine in obstetrics and neonatology have resulted in an increase in the percentage of survival of preterm infants and those with congenital anomalies, giving rise to newborns and children with chronic complex conditions (CCC). Among these, anyone who has a multisystemic, congenital or acquired disease that imposes functional, physical and/or mental limitations, requiring specialized technological support, such as multidisciplinary, drug, dietary and/or technological care (RABBIT; AQUINO, 2017; CORREIA; GONÇALVES, 2016).

The boundaries of fetal and neonatal viability have been expanded, and increasingly, newborns (NB) with CCC have survived, changing the epidemiological configuration of this population and making the use of technologies essential, not only to increase the survival rate, but also to provide care based on their specific needs (SOUSA et al.; 2017)

This specialized care is provided in a Neonatal Intensive Care Unit (NICU), an environment designed for premature and non-preterm NBs who present some type of problem at birth, consisting of essential devices and equipment for the care of these patients. In this unit, care must go beyond technical and scientific activities, thus requiring a look at the totality of everyone involved in the experience of caring for a seriously ill newborn (SILVA et al., 2017; MELO et al, 2016).

In the situation of newborns with CCC, admission to the NICU must not only aim to promote aggressive treatment, it must also help family members in making wise decisions regarding the survival and end of life of these NBs, that is,, the coexistence of palliative care (PC) decision is important and challenging (COELHO; YANKASKAS, 2017).

The concept of PC was given by the World Health Organization (WHO) (WHO, 2002) in 1990 and updated in 2002 and consists of the assistance/approach promoted by a multidisciplinary team, carried out through the prevention and relief of suffering, with the objective of promoting the quality of life of patients and their families who are facing diseases that threaten the continuity of life (INCA, 2020; MOURA, 2017).

In neonatology, care through PC has grown in recent years, with a concern to provide a quality service centered on the patient and family, through communication, assessment of treatment, pain and grief. The palliation approach must be performed by the multidisciplinary team, that is, all those who provide care to the newborn and his family, such as a doctor, nurse, social worker, physiotherapist, occupational therapist, psychologist, nutritionist, speech therapist, pharmacist and others. (CARDOSO; SILVA; LEAL, 2020; MOURA, 2017).

It is known that the moment of death for many professionals is permeated by different conflicts, feelings and emotions, which requires excellent technical-scientific training and professional and emotional preparation. On the other hand, it also requires from the professional the ability to manage situations that require teamwork as much as possible (OLIVEIRA; MARANHÃO; BARROSO, 2017; VICENSI, 2016).

In this sense, the participation of the family and the multidisciplinary team in all actions leads to a path of quality in the care provided to patients in palliative care, based on knowledge, respect and dignity (MOURA, 2017).

Braga and Queiroz (2013), studying the challenges of the health team in palliative care, concluded that there is a need for research on how professionals deal with palliation on a daily basis in its different stages of development, as death is still about a stressful experience.

The interest in studying the challenges of the multidisciplinary team in the context of palliative care in neonatology emerged from the academic and professional experience of the researchers in the Neonatal Intensive Care Unit, where professionals in a dilemma because they are unable to understand how a baby has just been born was observed. it would come to its “end” and have to be prepared for a “good death”. After searching for bibliographical references for the writing of this study, it was seen that there has not been much progress in this area either, especially in the field of neonatology, which gives a need for more studies and relevance to the topic.

It is believed that when discussing the professional feelings that permeate the moment of palliative care, it will be possible to find coping strategies for a better professional management of the palliative process, as well as facilitating the family experience. Therefore, the objective of this research was to know the experience of the multidisciplinary team facing palliative care in Neonatal Intensive Care Units.

METHODOLOGY

The present study was exploratory in nature and based on descriptive and qualitative research. The data collection techniques used were semi-structured interviews, recording (after permission from the subjects) and systematic observation.

As for the analysis and systematization of information, thematic content analysis was used according to Minayo (2016), so that the data were collected, organized and presented in three phases: 1st - characterization of the subjects participating in the study; 2nd- analysis of the speeches of the participants, extracted from the interviews that underwent pre-analysis and exploration of the material and 3rd- treatment of the results with interpretations of the research data.

The intention was to interview the entire multidisciplinary team involved in palliative care in the NICUs of the Assis Chateaubriand Maternity School, however the occurrence of the pandemic limited visits and times for collection, a total of twelve professionals being chosen for convenience: four nursing technicians, two physicians, one nurse, four physical therapists and one occupational therapist complying with the inclusion criteria such as: need for previous work in PC and a minimum of 1 year of work in the hospital unit of collection.

The interview was carried out at the institution itself and in its certain work shifts in the period from October 2020 to January 2021. In order to preserve anonymity, fictitious names were used for each of the Interviewed professionals, the choice was made by terms found in the statements of these professionals during the study as: Knowledge, Respect, Dignity, Calm, Attenuation, Relief, Proximity, Smoothness, Comfort, Continuity, Zeal and Reception.

The study met the fundamental ethical and scientific requirements, in accordance with the Guidelines and Regulatory Standards for Research Involving Humyears Beings, of the National Health Council, through Resolution No. 466/12 (BRASIL, 2012), with the approval of the Ethics Committee and Research (CEP) of the Maternity School Assis Chateaubriand, under opinion number 3,545,079. In this sense, an Informed Consent Form (TCLE) was formulated, signed in two copies, one in possession of the Interviewed and the other of the researcher, containing the objective of the study and guarantees of confidentiality of the subjects' identity.

RESULTS AND DISCUSSION

12 professionals were interviewed, characterized according to the table.

After the analysis of the participants' statements extracted from the interviews, exploration of the material and interpretation of the speech, 3 thematic axes emerged for the discussion of the study, presented as follows: "Working between life and death: Experiences in a NICU"; "Palliative care: when death is certain, what to do?" and "The palliation and the family."

TO WORK BETWEEN LIFE AND DEATH: EXPERIENCES IN A NICU

The first thematic axis was addressed through the following questions: What does the name of this theme tell you?; How do you see the ICU environment, what does it translate to you?; With these questions, we sought to capture the professional's perception in relation to their work environment in light of the challenges experienced.

Seeking to know the professional's vision of the NICU environment can show us the

Professionals interviewed	Education/Age	Acting time in UTIN	Experience in palliative care
Interviewed 1	Nurse, 34 years, specialist in pediatric nursing e neonatal and master in public health	11 years	sim
Interviewed 2	Médico, 43 years, specialist in pediatrics and neonatology	12 years	sim
Interviewed 3	Doctor, 48 years old, specialist in neonatology and palliative care	10 years	sim
Interviewed 4	Nursing technician, 38 years	4 years	Yes
Interviewed 5	Nursing technician, 27 years	5 years	Yes
Interviewed 6	Nursing technician, 25 years	5 years	Yes
Interviewed 7	Nursing technician, 27 years	4 years	Yes
Interviewed 8	Physical therapist,52 years, physiotherapy specialist neonatal and intensive care	5 years	Yes
Interviewed 9	Physical therapist,31 years, ephysiotherapy specialist pediatric and neonatal	4 years	No
Interviewed 10	Physical therapist, 38 years, doctor in biochemistry	6 years	No
Interviewed 11	Physical therapist,38 years, specialist in manual and postural therapy	6 years	No
Interviewed 12	Occupational Therapist, 40 years, Thanatology specialist	6 years	Yes

Table 1- Information from Professionals Interviewed

importance of the multidisciplinary team in this environment. Each professional has a different look, but at times the respondents' answers coincide with each other, as can be seen in the following statements:

> "Care in the ICU is not yet prepared for palliation, this is still very recent, very new for everyone, for us too, and the ICU environment doesn't translate that much, right, because it's full of apparatus, full of equipment, it's always full of bombs and that reminds you to fight for life, got it? And not a quieter, more serene environment, with a half light, something more, shall we say, welcoming, that could mean this palliation. So this ICU environment still needs to be prepared, or at least a space provided for these patients who are indicated for palliation" (Knowledge).

> "Nowadays I think it's calmer because I already dominate more, but it's always a tense environment, right, the more experience you acquire, the more you know what to do at the time, but it's still very tense really until today because there are many procedures, especially the Neo ICU because they are very delicate, right, so it requires a lot of care and attention from us all the time" (Respect).

> "It's a very context-heavy environment. When we are on a daily basis, we end up getting used to those situations we witness, but it is important for us to always be sensitive to what is happening, not for us as health professionals, but also for families who are there, who are participating. It's a heavy environment, with a lot of pain, a lot of suffering, a lot of stress for the professional, a lot of stress for the family, so it's not easy being in this environment. Slowly, unfortunately, it happens that people end up getting used to the environment, not that it's bad for us to get used to it. The point is that we cannot forget what happens. We always have to be attentive and sensitized to those issues of suffering and do our best to provide assistance that really improves the client's situation" (Dignity).

Araújo Neto et. al (2016) report in their study that the ICU is an environment exposed to overload of functions, noise, alarms, contacts with serious customers, unexpected situations, constant interrelationship between the same people in the team throughout the shift, as well as the excessive demand for safety, respect and responsibility towards the client in distress, contact with pain and imminent death. These factors are considered obstacles in communication with the interdisciplinary team, which constitutes a difficulty in improving the quality of care.

Azeredo (2016) highlights that the ICU environment generates intense demands and suffering for family members and patients, consuming them physical, mental and emotional energy. This author describes that it is always necessary to think of the family-patient binomial as a necessary care and guide of assistance within the ICUs, because when this does not guide the professional, suffering, anxieties, fears, feelings of impotence and a feeling of helplessness towards the patient.

PALLIATIVE CARE: WHEN DEATH IS CERTAIN WHAT TO DO?

The second thematic axis sought to know palliation through the eyes of each professional. Knowing how to start this care and the professionals' feelings in relation to the baby undergoing palliation was discussed, addressed through the following questions: "What is the meaning of palliation for you? ", "When does this care begin and when does it end? ", "How does it feel to know that a baby will go into CP (palliative care) ? "

When asked about the perception of palliation, professionals highlighted the importance of palliative care, always considering the patient's quality of life. A process that involves the newborn, the family and the team.

> "So for me palliation, it involves promoting comfort in all stages of life, including at the time of death, in the case of our patients it is babies, right, death is often inevitable, but we can always do something, right, both for the baby and for the family, so I think this is it: to promote comfort in all its fullness, even more, I think that a word that touches me a lot when talking about palliation is dignity. It is to promote dignity for this patient. What can we do to preserve his dignity, while he is alive, even at the moment of death" (Calm down).

> "It starts when the baby does not have a favorable prognosis. And it ends when we're going to break the news to the parents, since at that time we also have to be careful" (Zelo).

> "The meaning is to bring the family closer and share care with them, which is important, to understand in their view, because sometimes we do everything we can to save the baby, but the condition that this baby lives in is often with a quality of life is so bad and it disrupts the family so much and we wonder if this was really the best. That's why, from the beginning, bringing the family together to share and to define together how far we can go together with them" (Attenuation).

> "For me, palliative care sends me to produce comfort for that patient, while he has that period of life, to guarantee as much as he can not feel pain, that he can leave in a comfortable way" (Relief).

Palliative care arises when curative possibilities no longer yield the desired result. The focus is not the disease, but the patient's quality of life, which must be respected, informed and aware of the entire process that takes place. In the professionals' conception, the experience in palliative care is differentiated and demands greater care and technical and humanitarian preparation to interact satisfactorily with those who need care (OLIVEIRA; MARANHÃO; BARROS, 2017).

When asked about the feelings experienced when the baby undergoes palliation, some professionals report sadness for having created bonds with the baby and family. On the other hand, at the same time, most of them reported feeling useful to develop better strategies for the palliative process of that patient. This moment was accompanied by reflective pauses where professionals sought to better answer the question:

> "Yes... we feel... there is a feeling of impotence, because it is impossible not to feel powerless in the face of it, but at the same time, as I've been working longer, I feel very useful knowing that we are going to do the difference in this baby's life as well as in this family as well. So we are always creating new strategies so that this moment is a lighter moment, as we create the souvenir box when the baby is gone, we know that the baby will die, we create a box to take pictures of the baby, the baby's first weight, we collect positive facts so that when this baby died, the mother keeps this box of memories for her, so that's how it is" (Proximity).

> "Yeah, we get very sad because as I said, they spend a lot of time here with us and especially those who work during the day have a lot of contact with the mothers, I've already worked during the day, now I work at night, I have less contact. So you see all the history, all the suffering, this part of knowing the history of that patient, that family, so you suffer along with the family" (Suavidade).

> "When we talk about feeling, right, it goes beyond the professional. Being a mother too, there really awakens the mother's side of pain, of loss, of putting herself in the family's shoes, of putting herself in the mother's shoes. So it's painful, I won't say it's normal, it's painful, we end up really giving in, right. We're professionals, but we're also human beings, right, so that's how the sensitivity emerges more in these moments" (Calm down).

The experience of caring for babies who have a reserved prognosis, that is, who have no possibility of cure, leads health professionals to experience a mixture of feelings such as sadness, frustration, empathy with their parents and hopelessness about life. Thus, the need for psychological and spiritual support and the holding of meetings after neonatal death is highlighted, for group reflection, constructive assessment of the adopted therapeutic and palliative attitudes and expression of feelings (SILVA; SILVA; SILVA, 2019).

PALLIATION AND THE FAMILY

The third and last thematic axis sought the professional's perception of the family of a baby undergoing palliative care, so that we asked: ''Have you ever followed or shared the news of PC with a family and can you describe this moment?' ', ''In your perception, what is the family behavior towards the palliation process?"

When asked about the moment of the news of palliative care for the family, most reported not having participated directly as this moment is in charge of the palliative care committee of the institution. Those who have already followed this moment report many questions on the part of the family, feelings of sadness and denial. Some professionals claim to be emotional in this first contact with family members and attempt to host at that time:

> "So from the moment of the news no, because I'm not part of the palliative care team but in a way I take care of the palliative care patient but it's very difficult, they end up revolting against us at the beginning, it's that thing, right, as if trying to look for someone to blame for what happened, which is normal for human beings, to try to find someone to blame, thinking that it will solve your problem instead of sitting down, relaxing, trying to... absorb everything that was passed on to you and see what you will do from now on, right. The beginning is very difficult for the families, we suffer a lot, so because they become very resistant, they close themselves to us, and with time they will land more, they will accept, they will relax, then the contact with the team with the family, but in the beginning it is very difficult" (Comfort)

> "When I meet with the family, I always try to explain to them what our goal is because many people do not understand what palliative care is at such an early stage, and I try to tell them, to the family that we will support them, while the baby is serious and we will do everything to make it well and so the team often wonders ''is this baby palliative?" and gets a little sad, right, it seems ... but this feeling, we need to change because it's not about giving up, it's just strengthening and giving more quality to this baby, right?! Questioning the behaviors, being more precise in what you are going to do and that you cannot make mistakes to harm the baby, to cause more damage, this is the worst thing you can do, it is to try to be as less harmful as possible, to be as beneficial as possible " (Attenuation).

> "It's always a very, very difficult moment, the first moment is not what we do, it's the doctor. But we are part of a group of the palliative care committee that over time we meet every 15 days, every week, depending on the baby's condition, with a multi-team that is speech, physical, TO, doctor, nurse, social worker and psychologist and we will talk to parents about palliative care. Sometimes the baby doesn't die, but the baby goes home with a lot of sequelae, they take care of it and it's always a difficult time, a time when the parents cry a lot, it's a time that we have to give a lot of support, it's a moment when we cry together, it's impossible not to get emotional about some cases and that's how it is, it's a very difficult time". (Continuity).

Marchola et. al (2017) state that palliative care can transform a destructive experience into something that strengthens family ties and allows the professionals involved to offer comfort whenever possible, even though they cannot cure.

Alves, França and Melo (2018) highlighted in their study that the relationship between professionals and family members differs, some seek to know the family history and have greater involvement, others prefer distance, which was understood as a way to avoid suffering because death is a difficult event to experience, with a feeling of sadness and loss, and the need for self-care to face this moment.

Regarding the questioning of the professional's perception of family behavior in the palliative process, the participants stated that the way the family deals with this process depends a lot on their degree of understanding about palliative care, however, feelings of sadness, anger and questioning on the part of the family about the conduct performed. They also highlighted the importance of religiosity and spirituality as factors that help family members to go through this process.

> "The behavior is quite varied, right, it will depend a lot on the culture, on the issue of religiosity, on the issue of how the emotional process of each father, each mother is going. Because sometimes it generates a feeling of guilt, there are phases of grief that mothers go through, sometimes they stagnate in a certain phase of grief, they feel guilty, they blame God, they blame the team. There are other families who already accept that the baby is going to die or that he is going to return home with the tracheostomy, with GTT. It will depend a lot on the level of acceptance of each family and I think that this level of acceptance is very much related to the emotional issue and the issue of spirituality of each one" (Continuity).

> "This is very variable, there are some families, which is what I told you, it goes through this process of spirituality, religiosity, "I have such a religion, I accept it like that and I've already let go and etc..." or so "no, I don't accept death, it's very difficult for me", so there is this perception of the family to work on it and it is often difficult for the family to accept, because we put ourselves in the family's shoes and it is difficult for us to accept as a professional, we keep wondering why, who can say to a family that does not have this knowledge, that does not have this experience, so it is a daily walk, this family behavior, so you need to be very welcoming, very empathetic so that it can permeate in the best possible way" (Knowledge).

> "They don't accept it, there are some who seem to be anesthetized, but there are others who already revolt, they get very harsh with us, with time it gets better, their acceptance... it takes a while, but they end up accepting... they end up understanding what palliatives are because at first they think ''ah, my son is going to die" (Comfort).

> "Of the few I see, at first there is a refusal to know that your baby doesn't have that whole perspective, but there are some who accept it in accordance, in a lull, I think it has a lot to do with the spiritual side (Welcoming).

It was observed in the speeches above the intimate relationship between palliative care and spirituality, how to understand that a baby who has just been born already has the possibility of death? Palliation is still closely related to terminality and not to continuity, as Oliveira et al. (2019) mention that spirituality is the refuge of families, not only to relieve physical pain, but also emotional pain and relationships involved in the care process. It is, therefore, the necessary response to the clamor for spirituality of patients and families, such as the execution of superior well-being.

The training of professionals and the family will influence the care and zeal of patients whose disease is beyond the possibility of cure. In palliative care scenarios, the involvement of the family, which plays an important role in this process, is notorious. Welcoming must ensure that this family does not feel abandoned, from an emotional and psychological point of view, as a member's illness can disrupt the entire family itself, generating conflicts and feelings that are sometimes expressed through anger, tension and denial (ROSECRIM; MIRANDA; RIBEIRO, 2020).

CONCLUSION

The initiative to study the professionals' view of palliative care is quite challenging. Going deeper into the theme, seeking to understand how this palliation process takes place, as well as the challenges faced by these professionals, especially in relation to the family, highlights the importance of this care.

The professionals participating in this study had at least 1 year of experience in palliative care and each one of them was able to share their experience well. In their speeches, they emphasize the importance of an environment prepared for palliation, because in view of all the apparatus, equipment and noise, professionals say that the ICU environment still needs to be more humanized so that the palliation process is more welcoming, serene and quiet.

It is concluded that the professional's view of the palliation process is of great relevance, as it portrays the reality experienced by the team in the environment of high-risk units. Through the results, the need to develop strategies to facilitate this process is highlighted, with a focus on quality of life and comfort not only for the family and newborn, but also for the multidisciplinary team, which would benefit greatly from processes of specific qualifications aimed at the end-of-life care of newborns.

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