

## Perinatal palliative care in a university hospital: building an assistance protocol

### *Cuidados paliativos na assistência perinatal de um hospital universitário: construção de protocolo assistencial*

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#### ABSTRACT

**Introduction:** The practice of palliative care (PC) in perinatology brings a new horizon for integral assistance to the newborn/family-team care binomial. Standardizing dimensions for individualized care of perinatal PC can contribute to the full implementation of these practices in health care units for pregnant women and newborns. **Objectives:** To report the stages of construction of the Perinatal Palliative Care Protocol of the Neonatal Unit of the *Hospital das Clínicas da Universidade Federal de Pernambuco* (HC-UFPE) and propose a multidimensional care model. **Methods:** An experience report descriptive study, with proposition of assistance models in perinatal PC. The elaboration of the assistance protocol (AP) comprised 5 stages: 1) narrative literature review; 2) textual production and construction of multidimensional care models; 3) evaluation of the bioethical and scientific aspects of the PA by members of the Clinical Bioethics Service of HC-UFPE; 4) validation of the practical aspects of the implementation of the AP with the interprofessional team of the unit; 5) final evaluation of the PA by the head of the unit and superintendence of HC-UFPE. **Results:** The AP was developed from a comprehensive model of perinatal PC built from three dimensions of care - biological, bioethical and psychosocial - applied to six common situations of clinical practice in Perinatology. Together with the assistance, management and bioethical service teams, guidelines were defined for conducting situations of end-of-life of the newborn, incompatibility with life and limit of viability of the extremely premature newborn. **Conclusion:** The proposed AP seems to have potential to help teams to plan assistance in perinatal PC, aiming to offer the patient-family binomial a hospital experience with less pain and suffering.

**Keywords:** Palliative care; Perinatology; Bioethics; Health communication.

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## RESUMO

**Introdução:** A prática dos cuidados paliativos (CP) em perinatologia traz um novo horizonte para assistência integral ao binômio recém-nascido/família-equipe de cuidados. Padronizar dimensões para a assistência individualizada dos CP perinatais pode contribuir para implementação plena dessas práticas nas unidades de saúde de gestantes e neonatos.

**Objetivos:** Relatar as etapas de construção do Protocolo de Cuidados Paliativos Perinatais da Unidade Neonatal do Hospital das Clínicas da Universidade Federal de Pernambuco (HC-UFPE) e propor modelo assistencial multidimensional. **Métodos:** Relato de experiência com proposição de modelos assistenciais em CP perinatais. A elaboração do protocolo assistencial (PA) compreendeu 5 etapas: 1) revisão narrativa da literatura; 2) produção textual e construção de modelos assistenciais multidimensionais; 3) avaliação dos aspectos bioéticos e científicos do PA pelo Serviço de Bioética Clínica do HC-UFPE; 4) validação dos aspectos práticos da implementação do PA pela equipe interprofissional da unidade; 5) avaliação final do PA pela chefia da unidade e superintendência do HC-UFPE. **Resultados:** O PA foi elaborado a partir de um modelo integral de CP perinatais construído a partir de três dimensões assistenciais - biológica, bioética e psicossocial - aplicadas a seis situações comuns da prática clínica em perinatologia. As diretrizes foram definidas em conjunto com equipes de assistência, gestão e serviço de bioética para condução das situações de incompatibilidade ou final de vida do neonato e limite de viabilidade do recém-nascido prematuro extremo. **Conclusão:** O PA proposto tem potencial para auxiliar equipes a planejar a condução da assistência em CP perinatais, visando oferecer ao binômio paciente-família a vivência hospitalar com menos sofrimento.

**Palavras-chave:** Cuidados paliativos; Perinatologia; Bioética; Comunicação em Saúde.

## INTRODUCTION

The progressive technological improvement of perinatal health support generates an increase in newborn (NB) survival rates. However, in some NBs, all these advances can artificially maintain life, causing pain and suffering to everyone involved in care<sup>1-3</sup>.

Palliative Care (PC) is a scientifically and bioethically based multidisciplinary practice to add quality to life and the dying process. The PC acts preventing and relieving suffering, bringing a new horizon for comprehensive assistance to those involved in health care<sup>4</sup>.

Important requirements for PC practice in Perinatology are the improvement of communication between health professionals and the family<sup>5</sup>, the understanding and applying of bioethical principles in care<sup>6,7</sup>, and interdisciplinarity in case management, aiming at the best interests of the NB and their family members<sup>8,9</sup>.

Examples of situations that are difficult for the team to handle are the extremely premature limit of viability<sup>10-12</sup>, the incompatibility with life<sup>13</sup>, the definition of the end of life<sup>14</sup>, the unexpected worsening of the condition of the NBs<sup>15</sup>, communication and family support in case of suspicion of syndromic NB<sup>16,17</sup>. The existence of care protocols in PC can help to guide situations that are difficult to handle by health teams and promote engagement and uniqueness in handling more complex situations<sup>18-20</sup>.

The present work aims to report the stages of construction of the Perinatal Palliative Care Protocol of the Neonatal Unit of the Hospital das Clínicas of the Federal University of Pernambuco (HC-UFPE) and to propose a multidimensional care model.

## METHODS

This descriptive study, experience report type, proposes a care model in perinatal PC.

The elaboration of the care protocol (CP) comprised 5 stages: (1) narrative review of the literature; (2) textual production and construction of a multidimensional care model; (3) assessment of the bioethical and scientific aspects of the CP by members of the Clinical Bioethics Service at HC-UFPE; (4) validation of the practical aspects of the implementation of the CP with the unit's interprofessional team; (5) final assessment of the CP by the head of the unit and the HC-UFPE superintendence. Below is a more detailed description of what each stage of the construction of the CP consisted of:

### (STEP 1) NARRATIVE REVIEW OF THE LITERATURE

Databases and scientific documents from Brazilian medical entities were accessed. The bibliographical research was carried out in PubMed, SciELO, Scopus, and *Periódicos Capes* databases, selecting 25 articles considered relevant, especially if published in the last five years. Some keywords/descriptors used were: palliative care, perinatology, neonatology, prematurity, bioethics, and communication of bad news.

### (STEP 2) TEXTUAL PRODUCTION AND CONSTRUCTION OF A MULTIDIMENSIONAL CARE MODEL

The textual production of the CP aimed to use clear and concise written language. A model for comprehensive perinatal PC care was developed, built with three care dimensions - biological, bioethical, and psychosocial - applied to six common clinical practice situations in Perinatology (Figure 1).

Throughout the text of the CP, the following were also inserted: (1) neonatal severity scores, to determine the severity of the disease<sup>21</sup>, which were part of the biological dimension of the care model; (2) relevant aspects of

communication between health professionals and families of NBs and suggestions for dialogues based on the SPIKES Protocol for approaching, welcoming and assisting families<sup>22</sup>; (3) excerpts from the book "A Morte é um Dia Que Vale a Pena Viver," by Ana Cláudia Arantes<sup>23</sup> - this book was donated to the service for reading and raising awareness among the team.

### (STEP 3) EVALUATION OF THE BIOETHICAL AND SCIENTIFIC ASPECTS OF THE CP BY MEMBERS OF THE CLINICAL BIOETHICS SERVICE OF HC-UFPE

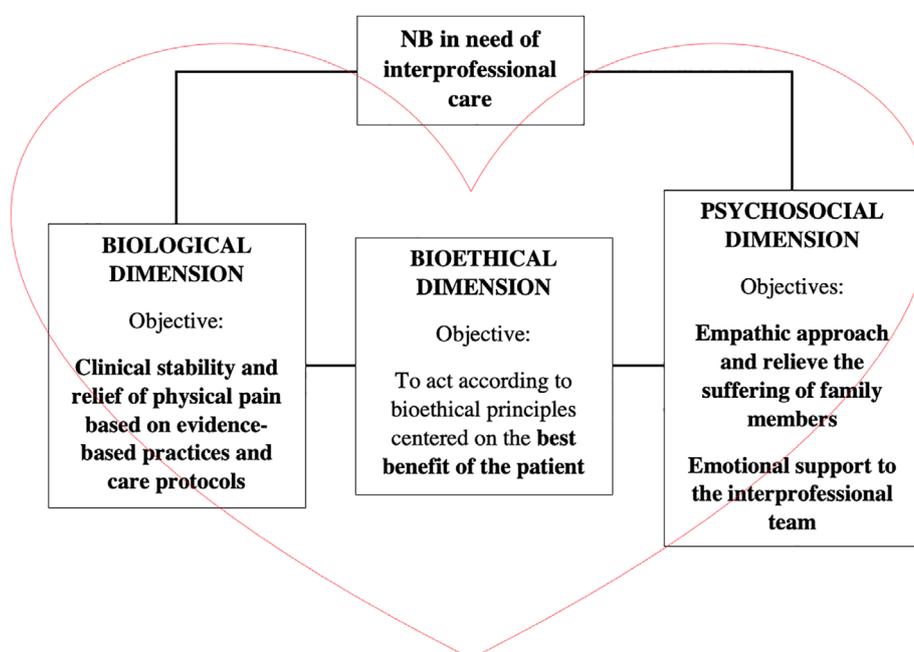
A positive opinion was issued by the institution's bioethics service for the implementation of the CP.

### (STEP 4) VALIDATION OF THE PRACTICAL ASPECTS OF THE IMPLEMENTATION OF THE CP WITH THE UNIT'S INTERPROFESSIONAL TEAM

During the ordinary care team meeting, 32 members of the unit's interdisciplinary team were present, including obstetricians, neonatologists, nurses, speech therapists, physiotherapists, pediatric intensivists, and residents. The topics of the CP were presented, and space was opened for any opinions for changes, criticisms, and suggestions to the text. There were no suggestions for changes to the CP topics. Some members present felt motivated to exemplify previous experiences whose existence of the protocol could have contributed to the presented outcomes.

### (STEP 5) FINAL ASSESSMENT OF THE CP BY THE HEAD OF THE UNIT AND THE HC-UFPE SUPERINTENDENCE.

The head of the unit and the hospital superintendent approved the completion of the CP. It was agreed with the managers to review and update every two years regarding the care aspects of the protocol.



**Figure 1.** Integral perinatal PC model.

## RESULTS

The CP was designed to implement a comprehensive model of perinatal PC (Figure 1). Three care dimensions - Biological, Bioethical and Psychosocial - constituted the care model proposed for all babies born at the unit. The justification for including all NB under the PC would be because they demand interprofessional care and represent a vital phase with great potential to develop life-threatening adverse situations while hospitalized.

### *THE BIOLOGICAL DIMENSION*

Caring for the biological dimension of the NB would involve compliance with clinical protocols with evidence-based practices validated by the entire interprofessional team.

Assessing pain signs in NBs would be the fifth vital sign to be investigated in daily care to provide the best possible comfort to NBs.

Neonatal scores for determining disease severity should be used as they would be well accepted as essential tools in intensive care units. However, the use of scores to predict individual outcomes would be limited to individual risk prediction and counseling.

### *THE BIOETHICAL DIMENSION*

Bioethics would bring balanced responses to current ethical conflicts based on four fundamental principles: autonomy (freedom to adopt decisions), beneficence (doing good), non-maleficence (not doing evil), and justice (ensuring resources are available to guarantee assistance dignified).

For the application of bioethical principles, there would be a need for a spirit of openness to dialogue that would allow each of those involved to approach each other, recognizing that everyone has something to teach, whether revealing a different perspective or providing transcendence, changes, revisions, enrichments, complementarities concerning the different points of view.

Conflicts in the bioethical sphere of the fetus/NB-family-health care team trinomial would be common in routine care. For implementing the CP, it would be important to adopt a preventive attitude towards potential conflicts. Adopting a broader perspective of care would be necessary for the preventive approach to avoid situations becoming dilemmatic, with only two possibilities, as they would bring a greater risk of judicialization of care.

Two provisions contained in the most recent Code of Medical Ethics<sup>14</sup> published in April 2019 (principle XXII and art. 41) determined that the physician should avoid performing unnecessary procedures and provide the patient with appropriate palliative care, always taking into account the expressed will of the patient or, if this is not possible, that of his legal representative.

Principle XXII provides: "in irreversible and terminal clinical situations, the physician will avoid carrying out unnecessary diagnostic and therapeutic procedures and will provide the patients under his care with all appropriate palliative care".

The sole paragraph of art. 41: "In cases of incurable and terminal illness, the physician must offer all palliative care available without undertaking useless or obstinate diagnostic or therapeutic actions, always taking into account the express will of the patient or, failing that, that of his legal representative".

The care plan would be an exercise in ethical deliberation, as it should consider the values and desires of the patient or his/her legal representative(s) in the first place, but the final decision would be up to whoever has the technical knowledge, i.e., to the accompanying physician, with the support of his work team.

In situations where disease-modifying treatment was not possible, it would be important to make the family aware of the need to avoid obstinate treatment measures that could cause distress to the NB.

The signature of a term for the parents to inform about the indication of palliation due to the irreversibility of the disease would not be necessary since, in hypothetical cases of judicialization, the burden of proof to the contrary would be on the complaining party. The best measure of protection and defense of the health professional would be the record in the medical records of all procedures, dialogues with the family, and evolutions performed.

### *THE PSYCHOSOCIAL DIMENSION*

Taking care of the psychic dimension of the family and the health professionals caring for the NB was an essential part of the CP.

For a better understanding, empathy, and support for the psychosocial dimension of the binomial mother/family-baby from the moment they enter the unit, it was suggested to include psychosocial aspects in the NB admission form, among which: religious aspects, including the possibility of domestic violence, main anguish/fear imagined by the pregnant woman/family, real and current reported situations that are difficult to cope with. Knowledge of this psychosocial sphere by the entire care team would enable a better empathetic approach with family members and promote relief of suffering in difficult situations that NBs may face during hospitalization.

The first visit of both parents to the neonatal intensive or intermediate care unit should be accompanied by a member of the interprofessional team so that the following objectives are achieved: (a) "planting the seed of good communication" from the beginning of hospitalization, to establish trust and respect from parents concerning the care to be provided by the entire team, in addition to establishing a positive, protective attitude and a loving bond towards the NB; (b) the exercise of "continued good communication," as parents and family members should be offered empathic listening and the necessary clarifications about the clinical condition of the NB, under the pillars of availability, privacy, uniqueness of information and respect for the opinions of the family in decision-making. Avoid conflicting information.

The privacy of family members' conversations with the medical and interprofessional team would be an objective to be achieved by structuring a private room for this purpose. Alleviating the suffering of family members could be achieved with the entire team's commitment. They would be ways of alleviating the suffering of the family: the establishment of sensitive and effective communication, the availability for active listening, the emotional support of the presence of the professional next to the family members in the difficult situations faced by the NBs, the respectful touch and the compassionate silence, the fundamental support of Psychology. The care with the emotional aspects of the interprofessional team would be presented in a specific protocol elaborated by the service psychologist.

In the CP, relevant aspects of professional health-family communication were described, and dialogues based on the SPIKES Protocol<sup>16</sup> were suggested. The CP recommended that, in situations where bad news is communicated, the environment should be private and the doctor should always be accompanied by another health professional, as well as the family member who received the news should be accompanied by a companion (in the absence of another family member at the hospital, consider another health professional with greater involvement with the family).

It was also suggested that the proposal for annual training of the team for communicating bad news, elaborated by two of the authors of the present work<sup>22</sup>, be maintained.

#### **THE DEFINITION OF THE END OF LIFE OF NEWBORNS**

Guidelines were defined for conducting end-of-life situations for newborns based on the interface of the three dimensions of the care model. It would be up to the medical team to define the end of life for a critically ill baby. The CP advised recording the following consensus items in the patients' records, individualized for each case:

- (1) Estimation of the probability of curing the disease: record the consensus information from the expanded study on the understanding of the disease, the available treatment, and possible limitations; use the various existing prognostic indices;
- (2) Obtaining the team consensus on the irreversibility of the disease: before reaching a consensus in the medical team on the irreversibility of the neonatal condition, this environment of uncertainty should not be extended to the family, as antagonistic information and conflicting perspectives would be expected on the part of members of the medical team regarding the therapeutic possibilities until a more precise definition was reached. For the most controversial cases, an opinion from the Clinical Bioethics Service should be considered, as well as an evaluation by the PC Committee. It is important to register promptly in the medical record when the consensus of irreversibility is defined, and the situation will be communicated appropriately to the family members.
- (3) Communication for family involvement in the decisions to be taken: when consensus is established within the medical team, the family should be progressively involved in the decision-making process through frank, objective, and serene discussions.

The entire healthcare team at the NNU should also be aware of the irreversibility of the baby's condition and the outcomes related to the stages of communication with the family. It would be important for family members to be heard, understood, and able to participate in decisions related to the end of their children's lives. During conversations with family members, calling the baby by name would be important to value him/her as the central subject of all care. Just as the medical team needed time to define the irreversibility of the neonatal condition, the family would also need time and concrete evidence to be convinced that the condition would be irreversible, unresponsive to treatment, and without disease-modifying treatment. Maintaining an environment of trust, respect and solidarity would be conducive to understanding. It would be a time to listen a lot and respond in a compassionate, objective, direct fashion, and as simple as possible to questions, avoiding technical jargon and statistical imprecision, which do not contribute at all on this occasion. Each family member would have their time of understanding. The evolution of understanding on the part of family members would tend to be slow, requiring several demonstrations of exams or clinical tests. Until there was this understanding about the irreversible stage of the disease, there would be no way to progress in the discussion to the stage of defining treatment priorities. The emotional support of the entire team involved and the psychological support would help the family members in these difficult times. The record of conversations with family members should be rigorously recorded in the medical record for the entire team's knowledge.

- (4) Definition of treatment priorities, objectives, and medical interventions: it would be important to reinforce the team's effort in anticipating possible interurrences, complications, or manifestations of the evolution of the baby's condition. The doctor in charge should communicate in advance with the family the conduct to be adopted in these eventualities, record the therapeutic plan in the medical record, as well as agree with the doctor on duty on its management in different situations, such as the occurrence of convulsive crisis, worsening of the condition breathing and/or apnea, digestive bleeding, etc. The principle of respect for the autonomy of family members could not exceed the limit in which they could be held accountable or feel guilty for the final definition concerning the therapeutic measures to be taken. The accompanying physician would decide who would be responsible for managing the case with the discussions already shared with the team. The exchange of information with the accompanying Psychologist of the family would be essential to help understand all involved in the care. There would be no prior definition of which therapeutic measure would be effective or futile, as this definition would be made on an individual basis, case by case, considering all factors related to the disease, centered on the best benefit for the patient, allied to the expectations of the NB-family members.

It is important to consider possible changes to make the hospitalization environment less stressful, more private, and comfortable for the baby and the family: seek less noise in the ICU and equipment; allow the entry of objects valued by the family for the baby (e.g., little toy, little book); encourage visits and meetings with other family members (e.g., aunts and uncles, siblings, cousins); arrange psychological support in advance for siblings who intend to visit the baby.

- (5) Support for family mourning: intensive support for the family was recommended from the moments before the baby's death and after the death. Communicating the irreversible deterioration and death to family members should be done in the most empathetic and compassionate way possible. Whenever possible, contact with family members should be carried out before the death occurs so that they can be offered the necessary support for the experience of the baby's death, thus contributing to the subsequent re-signification of mourning, avoiding the emotional damage of pathological mourning. The health professionals involved should be active in offering the support of presence, respectful touch, and compassionate silence that would bring comfort in these difficult moments, being totally discouraged from leaving the family member alone and helpless. At least one team member should be present, involved in providing care and attention to the family members, inviting the family member to snuggle the baby in his/her arms, but respecting the negative decision, should it arise. After the baby's death, special attention should also be given to the care team itself. It would be advisable to hold a meeting allowing everyone to express their feelings and criticism(s) regarding the care and treatment offered in that situation. This meeting would serve to assist in the elaboration of grief and to allow for adjustments and implementations in palliative care. Weeks after the death, a meeting with the bereaved parents and relatives could be encouraged to allow them to feel valued and comforted by re-discussing the death with the team that accompanied them.

In order to increase the accuracy of the application of the care model, six common clinical situations in the practice of Perinatology were established, namely:

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(Situation 1) The limit of the viability of extremely premature newborns;

(Situation 2) The NB without heartbeat at birth or the situation of cardiorespiratory arrest and neonatal death after hospitalization;

(Situation 3) The NB with a genetic or congenital condition incompatible with life;

(Situation 4) The NB with a high risk of death and/or potential reduction in the level of future quality of life;

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(Situation 5) The NB at risk of dying who, when receiving treatment, can survive with good quality of life;

(Situation 6) The NB at term or close to term, with a minimal risk factor for clinical worsening.

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These six clinical situations are detailed below:

*(Situation 1) The limit of the viability of extremely premature newborns*

One of the fundamental challenges in Perinatology would be to define the level of maturity of an extremely preterm NB, below which survival and/or acceptable neurodevelopment are extremely unlikely.

Bioethically, more important than saving the life of the extremely premature NB would be to give it a dignified life with its family. Therefore, it would be essential to welcome, understand and adequately inform these families about giving birth to these babies.

Each service should have its objective feasibility limit to know its ability to keep an NB alive with quality of life. It would be valuable information that would help parents and staff to make bioethically informed decisions. This viability limit could change over time, depending on issues related to the complexity of the evolution of perinatal and neonatal care. The care team should be aware of and re-evaluate at least every three years the consensus on the viable limit of extremely premature infants in the service itself.

Most services established the NB approach based on assessing the gestational age (GA), the parents' desire, and the fetal and NB conditions soon after birth.

The GA information often would be unknown or unreliable; in these cases, the birth weight could be used as one of the parameters to indicate the measures to be taken at the time of delivery. In these situations, birth conditions should be considered, assessing whether the child has a heart rate above 60 bpm, respiratory effort, and limb movement.

As for the mode of delivery, the cesarean section would not offer any benefit to fetuses with a GA of 22 to 24 weeks and would increase the maternal risk; therefore, for these cases, the high route would only be indicated for obstetric reasons; in the GA of 25 to 26 weeks, cesarean delivery could occur due to maternal or fetal indication.

If GA <23 weeks or birth weight <400 g, considering the best benefit for the baby, most protocols agreed that comfort measures should be taken, including providing warmth and coziness with the parents.

If GA 23 to 24+6 weeks or birth weight 400 to 500g, considering the uncertainty of the prognosis (gray zone) with a very low survival rate, the NB could be resuscitated or not, respecting the parents' wishes, which they should already be aware of the viability limit of the service, whose information should have already been passed on to them previously in a private and empathetic-compassionate conversation by the members of the interdisciplinary team.

It would be important to reinforce to the family members that the baby's HR response to the maneuvers would be a critical parameter to decide whether or not to continue the procedures; if the HR normalized, the baby should receive all procedures during resuscitation and then be taken to the intensive care unit (ICU); if there were no improvement in HR, advanced support measures would be interrupted to offer comfort measures; it would not be indicated, if there was no response to ventilation, to associate cardiac massage and drugs.

If GA 25 to 25+6 weeks or birth weight  $\geq 500$ g, considering the survival rates, neonatal resuscitation would be indicated, performing all the necessary steps; the baby would be admitted to the ICU and receive all the intensive care it needs.

*(Situation 2) The NB without a heartbeat at birth or the situation of cardiorespiratory arrest and neonatal death after hospitalization*

In cases of newborns who were born without audible heartbeats (not belonging to Situations 1 and 3 described), all resuscitation maneuvers should be initiated. This situation would also be applied to newborns under intensive and semi-intensive rooming-in and Kangaroo care who progressed to cardiorespiratory arrest.

If, after 10 min of resuscitation with all procedures properly performed, the child still has no heartbeat, the Neonatal Resuscitation Program<sup>20</sup> suggested the interruption of procedures.

Health professionals involved in resuscitation should provide the necessary support to family members. Whether in the delivery room or the neonatal unit environment, the mother and companion would probably be aware that something was not evolving well with the baby, given all the dynamics of movement of professionals during resuscitation. It would be important that, from the beginning of care, the health professional verbalizes that "the baby (call by name) was not born with a beating heart (or that the heart has stopped beating) and that we are doing maneuvers to try to make the heart return. Shoot down". This information would already prepare the emotional dimension of the mother and companion for the more sad news of the death that could follow.

If the mother did not have a companion of choice in the delivery room or the neonatal unit environment, a health professional from the team should remain by her side, offering her support, either in silence and/or clarifying doubts about what was happening with the baby.

After 10 minutes of unsuccessful resuscitation, the news of the baby's death should be communicated to the mother and companion, considering the following points:

- (a) if the mother is at risk for obstetric complications in the delivery room, it would be preferable to wait for the control of these complications to communicate the news, as there could be a worsening of her vital signs after learning the fact;
- (b) carry out difficult communication in the most empathetic and compassionate way possible; the health professional should be accompanied by another member of the team, just as the pregnant woman should have a companion of her choice

at the time of the news; the word "death" should be present in the dialogue; avoid detours to paths in communication that may raise doubts about the existence of death; active listening to family members would be extremely important.

*(Situation 3) The NB with a genetic or congenital condition incompatible with life*

The list of malformations incompatible with life is restricted and can be modified over the years based on biotechnological development. The following are part of the prognostic situations of incompatibility: anencephaly/acrania, holoprosencephaly, large encephaloceles, acardia, Potter's syndrome, thanatophoric dysplasia, osteogenesis imperfecta type 2, trisomy of chromosomes 13 and 18 (the latter is already underway with studies on palliative surgeries).

In cases incompatible with life, the approach to care for newborns should be restricted to comfort measures, according to the bioethical principle of non-maleficence. However, applying this principle would require a high involvement of the health team with the pregnant woman and her family, which should have started from the beginning of the prenatal diagnosis, allowing time and reflection to understand the baby's condition.

It is common for team professionals to face a lack of information and involvement with family members when the time of delivery comes, which would make it difficult to decide on the best course of action; in those cases in which a better involvement with the family members has not been established, no definitive decision should be taken, being more prudent to initiate resuscitation maneuvers and transfer the baby to the ICU. Subsequently, the diagnosis could be established through a complete and thorough clinical evaluation, associated with the results of imaging and laboratory tests.

Faced with newborns diagnosed with situations incompatible with life, the team should welcome parents and family members in the most empathetic and compassionate way possible, explaining the diagnosis, prognosis, and options for maintaining advanced life support or offering comfort. Most of the time, at the first moment, the parents could request that advanced support measures be maintained. As the days went by, observing the baby's suffering, the parents realized that the best thing would be to stop the more aggressive treatment and start the comfort measures. Allowing this period for the parents to process all the information and perceive the conditions of the child would facilitate the moment of loss and mourning, allowing a dignified death for the baby.

The example of team learning at HC-UFPE was cited in the CP after assisting conjoined twins with complex heart disease incompatible with life that occurred in the service in January 2019, where there was fundamental support from the Clinical Bioethics Service of HC-UFPE and the Psychology. The patient-family binomial was offered the experience of an outcome with less pain and suffering. Reflections on the case further reinforced the need for greater integration between prenatal care and hospitalization services<sup>24</sup>.

*(Situation 4) The NB with a high risk of death and/or potential reduction in the level of future quality of life*

It included NBs with a high-risk score for death and/or with a poor prognosis for future quality of life in surviving cases, such as hypoxic-ischemic encephalopathy, difficult-to-control infections, NBs who evolved with morbidities associated with prematurity, decompensated hydrocephalus, complex operable heart diseases, severe adverse care events, etc.

The long and intercurrent hospitalization of these NBs would be common in this situation, which would have a strong potential to generate conflicts between family members and the health team. Building a bond with family members, under the pillars of good communication, would be a determining factor for the success in handling these cases.

From the first day of hospitalization, the health team's communication with family members should follow the assumption of the slow and progressively bearable truth, inserted in a context of strong empathy and compassion.

It would be essential that, at least the first visit of each family member to the neonatal unit, could be accompanied by a health professional from the team, whether a doctor or not, who is aware of the baby's clinical case, so that it could provide the emotional support of the presence next to the family member, clarifying possible doubts that could be informed and identifying the potential fears of the family member in the face of their new scenario of coping. The impressions of this first contact of the professional with the family members should be promptly recorded in the medical record in order to inform the interprofessional team of day laborers and on-duty workers about the feelings that are permeating the psychosocial dimension of the baby's family, to enable everyone to get more effective and centered on the needs of the baby and its family during hospitalization.

The health team should play an active role in promoting the bonding of family members with the baby, promoting attachment through skin-to-skin contact and daily invitations for routine care.

In cases where the baby evolved with irreversible clinical status, the guidelines in the previous topic, "Definition of the End of Life for Newborns," should be followed.

*(Situation 5) The NB at risk of dying who, when receiving treatment, can survive with good quality of life*

It would include NB with presumably treatable conditions without relevant sequelae, e.g., term or near-term infants taken to intensive or semi-intensive units for respiratory distress and perinatal infections.

Establishing a good bond with the family members through good communication would be essential for conducting the case. The multidisciplinary team needs to clarify to the family members that during the treatment, the baby would be exposed to possible negative health events that could occur after hospitalization, such as infection. The professional should always be available and prepare the family for possible changes in perspectives in case there

is an unexpected negative evolution of the baby's clinical condition: "we will observe how your baby reacts to the treatment, and we will inform you of any worsening, if any."

The health team should interpret the progressive improvement after the treatment institution as an ever-present opportunity to encourage the family members to bond with the baby by promoting attachment through skin-to-skin contact or the daily invitation to a routine care system.

*(Situation 6) The NB at term or close to term, with a minimal risk factor for clinical worsening*

In this situation, NBs with a minimal risk factor for worsening and death would be included, e.g., mild respiratory discomfort after birth, jaundice, NBs coming from Rooming-in/Kangaroo to compensate for hypoglycemia, regurgitation, etc.

Special attention should be given to newborns and their families in cases with minor malformations and more frequent genetic syndromes, such as Trisomy 21 (T21). There are specific protocols to help in the communication and management of these cases<sup>17,18</sup>, and the health professional must be available to clarify doubts, provide a positive perspective for the future of the NB in light of the social and health support available and refer family members who need greater emotional support to Psychology.

The news about the suspected T21 should be a welcoming moment that stimulates the bond with the baby and brings positive perspectives to the family members. Some steps should be followed: (1) more than one team member should agree with the characteristic phenotype of the baby; (2) the person in charge for the communication would be the pediatrician who could be in the company of the obstetrician or another member of the team; (3) the news should be transmitted as soon as possible, even if the diagnosis is suspected but not yet confirmed; (4) the communication to the mother should be carried out in the presence of the father or a significant relative, and in the absence of these, the pediatrician should report that he would be responsible for talking again with the other relative when he was present; (5) talk about the diagnosis in a private and comfortable environment, free from interruptions, allow time for questions and make plans for a follow-up; (6) ensure skin-to-skin contact between the mother and companions and the baby, before starting the dialogue; (7) use sensitive, careful, confident language and call the baby by the name; (8) avoid language with value judgments, such as "I have bad news", "I'm sorry".

In situations that require brief clinical observation, such as mild respiratory discomfort in the first hours after the birth of the NB, consider the possibility of not separating or limiting the separation of the mother/family-baby binomial to a minimum. The benefits of skin-to-skin contact between the baby and the mother or family members could provide greater comfort, faster and more effective improvement of symptoms, and reduce the admission of these NBs to intermediate care units.

## DISCUSSION

This CP aimed to standardize dimensions of comprehensive care in common situations of clinical practice in Perinatology, respecting the complexity and individuality of each case to be experienced by the binomial baby/family team. It was considered that all NBs and their families, from pregnancy onwards, should be assisted by the interprofessional team in a *pallium* way (from Latin, protective mantle)<sup>25</sup>, that is, in the form of protection that could extend to the biological psychosocial spheres and bioethics.

In the perinatal period, the highest rates of childhood morbidity and mortality occur, in addition to unexpected, potentially life-threatening events. Considering that every baby and its family should be included in the philosophy of palliative care could bring a potentially preventive perspective of conflicts in communication between family and team and provide everyone involved with greater comfort in the emotional and biological spheres. The six common situations described in practice in Perinatology could help better frame clinical cases for assistance, research, and management purposes.

This protocol would require continued and critical evaluation by interprofessional teams to achieve the expected benefits. One of the challenges found in the construction of the CP was the critical participation of the interprofessional team members, which were still not very present in the meeting to validate the practical aspects (Step 4). A greater participation of the team in the next reassessments is expected, as the proposed comprehensive PC care model could be improved as it was experienced and periodically reassessed. After completing the five construction stages, the CP is put into practice. Every two years, a bibliographic and written text update will be provided (Steps 1 and 2) for re-submission of the protocol to the Bioethics Service (Step 3), to the interprofessional team (Step 4), and the management (Step 5).

The existence of the clinical bioethics service in the service has been encouraging discussions and team learning in the face of dilemma situations, which are difficult to handle with family members. In the same way, the PC commissions enriched the clinical conduct in opportune acquisitions of theoretical-practical and human knowledge.

To make the reassessment of care practices in PC more objective, it would be essential to know the periodic records of the unit's indicators that would provide a continuous flow of evaluation, action, and reassessment in the face of care measures. The experiences arising from the results of qualitative and quantitative scientific work carried out in the unit should also be added to the next versions of the CP to support actions and encourage better knowledge and understanding of the team regarding the impacts of interprofessional assistance on NBs, their families and on the care team itself.

## FINAL CONSIDERATIONS

This protocol aims to assist interprofessional teams in comprehensive PC care in common clinical practice situations in perinatology. The interconnection of the biological, bioethical, and psychosocial dimensions can facilitate the use of the PC philosophy, respecting the complexity and individuality of each case to be experienced. It is planned to update the bibliography and reassess the CP every two years, revisiting the five stages of construction and co-construction with all those involved.

## AUTHOR CONTRIBUTIONS

All authors contributed to all phases of protocol implementation and writing of the work.

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