

## **Positive and negative aspects of Palliative Care in Perinatology and Neonatology from the perspective of a multi-professional team**

**Aspectos positivos e negativos dos Cuidados Paliativos em Perinatologia e Neonatologia na perspectiva de uma equipe multiprofissional**

**Aspectos positivos y negativos de los Cuidados Paliativos en Perinatología y Neonatología desde la perspectiva de un equipo multiprofesional**

Received: 03/13/2022 | Reviewed: 03/21/2022 | Accept: 03/25/2022 | Published: 03/31/2022

**Fernanda Pegoraro de Godoi Melo**

ORCID: <https://orcid.org/0000-0002-0725-6602>

Londrina State University, Brazil

E-mail: [fernanda@lucibaena.com](mailto:fernanda@lucibaena.com)

**Marcelle de Oliveira Peripolli**

ORCID: <https://orcid.org/0000-0001-8717-510X>

Londrina State University, Brazil

E-mail: [marcelleppl@gmail.com](mailto:marcelleppl@gmail.com)

**Nilson Willamy Bastos de Souza Júnior**

ORCID: <https://orcid.org/0000-0001-7072-5320>

Londrina State University, Brazil

E-mail: [jrwbastos@gmail.com](mailto:jrwbastos@gmail.com)

**Adriana Valongo Zani**

ORCID: <https://orcid.org/0000-0002-6656-8155>

Londrina State University, Brazil

E-mail: [adrianazanienf@gmail.com](mailto:adrianazanienf@gmail.com)

**Vanessa Suziane Probst**

ORCID: <https://orcid.org/0000-0003-1483-5319>

Londrina State University, Brazil

E-mail: [vanessaprobst@gmail.com](mailto:vanessaprobst@gmail.com)

### **Abstract**

**Objetives:** to identify positive and negative aspects in the palliative care assistance of pregnant women with detected fetal abnormalities and/or newborns with poor prognosis, according to the perception of a multidisciplinary team in a university hospital. **Methods:** descriptive study with a qualitative approach with professionals from the maternity unit, obstetric emergency room and neonatal intensive care unit. Data collection took place from June 2018 to May 2019, through semi-structured interviews. The Critical Incident Technique was used. **Results:** the study sample consisted of 56 professionals from the multidisciplinary team. 236 critical incidents emerged, 88 with positive aspects and 148 with negative ones. **Conclusion:** it was possible to identify a more significant number of negative references to the detriment of positive ones regarding palliative care, demonstrating that such approach involves more difficulties for its proper implementation. This study provided information that might enable the development of measures to improve palliative for this population and to promote a perinatal and neonatal palliative care group implementation with periodic training and education for the multidisciplinary team.

**Keywords:** Palliative care; Perinatology; Neonatology; Patient care team.

### **Resumo**

**Objetivos:** identificar aspectos positivos e negativos na assistência em cuidados paliativos de gestantes com anormalidades fetais detectadas e/ou recém-nascidos com mau prognóstico, segundo a percepção de uma equipe multiprofissional de um hospital universitário. **Métodos:** estudo descritivo com abordagem qualitativa com profissionais da maternidade, pronto-socorro obstétrico e unidade de terapia intensiva neonatal. A coleta de dados ocorreu de junho de 2018 a maio de 2019, por meio de entrevistas semiestruturadas. Foi utilizada a Técnica de Incidentes Críticos. **Resultados:** a amostra do estudo foi composta por 56 profissionais da equipe multiprofissional. Emergiram 236 incidentes críticos, 88 com aspectos positivos e 148 com aspectos negativos. **Conclusão:** foi possível identificar um número mais significativo de referências negativas em detrimento das positivas em relação aos cuidados paliativos, demonstrando que tal abordagem envolve mais dificuldades para sua correta implementação. Este estudo forneceu informações que irão possibilitar o desenvolvimento de metas para melhoria em cuidados paliativos

para essa população e promover a implantação de grupos de cuidados paliativos perinatais e neonatais com treinamento e educação periódica da equipe multiprofissional.

**Palavras-chave:** Cuidados paliativos; Perinatologia; Neonatologia; Equipe multiprofissional.

### **Resumen**

**Objetivos:** identificar aspectos positivos y negativos en la asistencia en cuidados paliativos de gestantes con anomalías fetales detectadas y/o recién nacidos con mal pronóstico, según la percepción de un equipo multidisciplinario en un hospital universitario. **Métodos:** estudio descriptivo con abordaje cualitativo con profesionales de la unidad de maternidad, urgencias obstétricas y unidad de cuidados intensivos neonatales. La recolección de datos ocurrió de junio de 2018 a mayo de 2019, a través de entrevistas semiestructuradas. Se utilizó la Técnica del Incidente Crítico. **Resultados:** la muestra del estudio estuvo compuesta por 56 profesionales del equipo multidisciplinario. Surgieron 236 incidentes críticos, 88 con aspectos positivos y 148 con aspectos negativos. **Conclusión:** fue posible identificar un número más significativo de referencias negativas en detrimento de las positivas con respecto a los cuidados paliativos, lo que demuestra que tales enfoques implican más dificultades para su adecuada implementación. Este estudio proporcionó información que podría permitir el desarrollo de medidas para mejorar los cuidados paliativos para esta población y promover la implementación de un grupo de cuidados paliativos perinatales y neonatales con capacitación y educación periódica para el equipo multidisciplinario.

**Palabras clave:** Cuidados paliativos; Perinatología; Neonatología; Grupo de atención al paciente.

## **1. Introduction**

In the last 30 years, several advances have occurred in neonatal care. Newborn babies previously considered nonviable, such as extremely preterm infants and infants with severe congenital malformations, had their survival rates increased over time. However, the survival of these babies is sometimes related to severe sequelae and prolonged suffering of these patients, their families and the medical team involved, which can generate ethical dilemmas (Kilcullen, 2017) (Currie et al., 2016).

In the face of seriously ill newborns who do not respond to established therapy or pregnant women of fetuses with severe malformations or life-limiting conditions, the need of discussion of a basic concept arises: the Palliative Care (PC).

In 2007, World Health Organization (WHO) defined PC as an approach to improve quality of life of patients and their families facing a life-threatening disease, through early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual issues (Gomes et al., 2016). The International Association for Hospice and Palliative Care (IAHPC), a WHO-related, non-governmental organization, has adopted a new definition of PC, which applies to individuals of all ages, regardless of their diagnosis, prognosis, place of care or socio-economic status, and focuses on alleviating suffering caused by severe illnesses. In order to promote such care, a therapeutic approach by a multidisciplinary team is necessary (Radbruch et al., 2020) (Figueredo, 2013).

Considering that such approach is not yet a systematic practice in some hospitals, including the hospital where this study was conducted, and that pregnant women with detected fetal abnormalities as well as newborn babies with poor prognosis represent a great challenge for the multidisciplinary team, especially in the way these professionals perceive the assistance of these patients and their families, this study aimed to identify positive and negative aspects related to the assistance of this population, according to the perception of a multidisciplinary team in a university hospital.

## **2. Methodology**

This is a descriptive study with a qualitative approach. Sample consisted of professionals from the maternity unit, obstetric emergency room and neonatal intensive care unit (NICU) of a university hospital located in Southern Brazil. This Maternal-Infant unit is a reference for high-risk pregnancy. Inclusion criteria consisted in professional with at least 6 months of experience in the maternal-infant assistance and who had performed care of pregnant women with detected fetal abnormalities and/or newborns with poor prognosis. Professionals who were on vacation or on leave during data collection period were excluded.

Data collection took place from June 2018 to May 2019 with a sampling strategy using a snowball sampling method. The number of participants were not established at first, as the researchers were careful to include professionals from different occupations, involving all shifts, in order to obtain a more comprehensive perception from the multidisciplinary team. Data collection was completed after contemplating the representation of all professional categories involved in the multidisciplinary team.

Data were obtained through an instrument which has two parts: the first referring to professionals' characterization, and the second referring to the object of the study containing 3 questions.

**Table 1.** Guiding functions chart.

1- We ask you to think about a specific situation at your job, in which you witnessed or had to take a decision/conduct regarding treatment/care of pregnant women with detected fetal abnormalities and/or newborns with poor prognosis. Tell us in detail about how the situation happened, the actions taken and the consequences of that.
2- We ask you to think about a positive situation at your job in which you witnessed or assisted pregnant women with detected fetal abnormalities and/or newborns with poor prognosis and their family. Tell us in detail about how the situation happened, the actions taken and the consequences of that.
3- We ask you to think about a negative situation at your job in which you witnessed or assisted pregnant women with detected fetal abnormalities and/or newborns with poor prognosis and their family. Tell us in detail about how the situation happened, the actions taken and the consequences of that.

Source: Authors.

The Critical Incident Technique theoretical methodological framework (Silva et al., 2016) was used to identify positive and negative aspects besides decision-making or conducts regarding the assistance of pregnant women with detected fetal abnormalities and/or newborns with poor diagnosis along with their families, according to the multidisciplinary team's perception.

The interviews were individual, recorded and carried out in private places chosen by the participants within the work environment, respecting their availability, privacy, anonymity and interest in participating. The interviews lasted approximately 30 minutes and were carried out by 6 undergraduate nursing students, who were properly trained. The main researcher was not involved in the interviews since she is part of the unit's medical team, which could have led to bias had she conducted the interviews. After recorded, interviews were properly transcribed and analyzed.

Data analysis followed four steps: reading of transcribed reports; identification of elements that comprise the critical incident; reports grouping; and categorization (Flanagan, 1973).

The Research Ethics Committee of the State University of Londrina approved this study following Resolution 466/2012. All research participants signed informed consent form.

### 3. Results and Discussion

The study sample consisted of 56 professionals from the multidisciplinary team as shown in Table 2.

**Table 2.** Category of Health Professionals Interviewed.

<b>Professionals</b>	<b>Abbreviation</b>	<b>N</b>
Obstetric Emergency Room Practical Nurse	OERP	4
NICU/Intermediate Care Practical Nurse	NICUP	14
Maternity Ward Practical Nurse	MATP	1
NICU/Neonatal Intermediate Care Registered Nurse	NICUR	4
Obstetric Registered Nurse	OBSTR	3
Neonatologist	NEO	5
Obstetrician-gynecologist	OB-GYN	2
Psychologist	PSYCH	1
Physiotherapist	PHYSIO	3
Pediatric Resident Physician	PEDRP	4
Neonatology Resident Physician	NEORP	5
Obstetric-Gynecology Resident Physician	OB-GYNRP	3
Obstetric-Gynecology Resident Nurse	ON-GYNRN	1
Neonatology Resident Nurse	NEORN	6

Source: Authors.

Regarding the demographic profile of the 56 participants, most of them were female (91%). Median age was 32.5 [27.25-32.5] years, with majority of people aging between 24 and 59 years (87.5%). As to marital status, almost half of participants were single (46.4%), with a weekly workload of 40 hours (53.6%). Most of professionals interviewed were physicians (33.9%), practical nurses (33.9%) and registered nurses (25%).

In regard to work experience, more than half of participants have less than 10 years of experience (60.7%). However, when analyzing the average years of experience for each unit services, professionals working in the NICU, maternity ward and obstetric emergency room have, respectively 6.8, 9.8 and 10.3 years of experience. More than half of study participants (58.9%) were graduated in a residency program as shown in Table 3.

**Table 3.** Demographic profile of the multidisciplinary team. Londrina - PR, 2020.

VARIABLES	N	%
<b>SEX</b>		
Female	51	91
Male	5	9
<b>AGE</b>		
≤ 24 years	5	8.9
24- 59 years	49	87.5
≥ 60 years	2	3.6
<b>MARITAL STATUS</b>		
Married	19	33.9
Single	26	46.4
Civil Union	3	5.4
Divorced	8	14.3
<b>WEEKLY WORKLOAD</b>		
20 hours	8	14.3
40 hours	30	53.6
60 hours	18	32.1
<b>OCCUPATION</b>		
Physician	19	33.9
Nurse	14	25
Physiotherapist	3	5.3
Psychologist	1	1.9
Practical Nurse	19	33.9
<b>WORK EXPERIENCE</b>		
≤ 10 years	34	60.7
11- 20 years	16	28.5
≥ 21 years	6	10.8
<b>COMPLEMENTARY ACADEMIC EDUCATION</b>		
Residency program	33	58.9
Continued Education Course	10	17.9
Masters degree	5	8.9
PhD	4	7.1
PostDoc	1	1.9
None	3	5.3

Source: Authors.

### Critical Incident Identification

Overall, 168 reports were obtained, of which 18 were excluded for not fitting the critical incident technique. From the 150 remaining reports, 236 critical incidents emerged, 88 with positive aspects and 148 negative aspects. Regarding decision-making and conducts, 80 critical incidents emerged (with 28 positive aspects and 52 negative). The positive and negative references differentiation was made by the professionals participating in the study.

As to professional reports according to their occupation, in general, it was identified that negative responses regarding palliative care in perinatology and neonatology stood out over the positive ones, regardless of their academic background, as shown in Table 4.

**Table 4** – Occupational distribution in face of positive and negative references related to assistance of pregnant women with detected fetal abnormalities and/or newborns with poor prognosis along with their families. Londrina – PR, 2020.

Occupation	Positive References	Negative References	Total
Practical nurse	15	35	50
Physician	43	65	108
Nurse	24	38	62
Physiotherapist	4	7	11
Psychologist	2	3	5
<b>Total</b>	<b>88</b>	<b>148</b>	<b>236</b>

Source: Authors.

Incidents were classified into ten categories as shown in Table 5.

**Table 5** – Category distribution with positive and/or negative references extracted from critical incidents. Londrina – PR, 2020.

Categories	Positive References	Negative References	Total
Prenatal	19	17	36
Multidisciplinary assistance	8	4	12
Divergence of conducts	0	32	32
Delivering bad news	6	23	29
Unit's physical structure	0	2	2
Families emotional aspect	0	20	20
Multidisciplinary team emotional distress	0	21	21
Eligibility criteria	5	14	19
Family beliefs	10	14	24
Family insertion	40	1	41
<b>TOTAL</b>	<b>88</b>	<b>148</b>	<b>236</b>

Source: Authors.

In the Prenatal category, most positive responses were related to a specific case of a pregnancy of Siamese babies, in which both the mother and her family were followed up during prenatal care, which enabled a better acceptance of death. Negative responses, on the other hand, were related to lack of communication and poor elucidation to the mother and her family about the severity of fetuses detected with life-limiting conditions.

About the Multidisciplinary Assistance category, positive references were mainly related to multidisciplinary meetings participation, where professionals from different areas have active voice to help promoting PC in the best way possible. Some perceived the lack of better communication between the all types of health care professionals as a negative aspect, which could lead to divergence of conducts.

The Divergence of Conducts category had only negative references, most of which were related to divergences in treatment approach leading to unnecessary prolonged suffering of the child and his/her family.

Regarding the Delivering Bad News category, positive responses referred mainly to proper clarification of patient's condition which allowed comforting and welcoming measures to help family to better deal with the situation. Negative responses were related to innappropriate approaches of health care professionals at the time of delivering bad news.

The Unit's Physical Structure category received only negative feedback, mostly related to the absence of individualized spaces that could provide the family and the baby some proper privacy.

As to Families Emotional Aspects category, it also received only negative responses as professionals report that factors such as sadness and family suffering are considered as hindering elements for palliative care.

The negative responses were unanimous in the Multidisciplinary Team Emotional Distress category, who pointed out that health care professionals also need support and comfort in order to feel strengthened for palliative care.

In the Eligibility Criteria category, positive feedbacks were related to early and promptly detection of babies with poor prognosis which enabled the multidisciplinary team to take comfort and humanization measures in advance. Negative aspects were generally related to excessive interventions, even in situations where babies' survival was considered impossible.

About the Family Beliefs category, the positive references reported families' faith as an important source of comfort. However, the negative aspects declared some situations where the families have a difficult time accepting the confirmed diagnosis and condition's severity and desperately hope for a miracle to happen, rejecting palliative care and leading to situations that might lengthen suffering for all parties involved.

Regarding the Family Insertion category, positive responses were associated with situations in which the health care team understood the family insertion importance in palliative care and were able to promote it, negative responses reported some health professionals difficulty on being aware of family presence and ending up acting inappropriately or insensitive to the families' weaknesses.

**Table 6.** Multidisciplinary Team's Speeches.

	<b>POSITIVE</b>	<b>NEGATIVE</b>
<b>PRENATAL</b>	“(….)I had the opportunity to follow up a pregnant woman with Siamese fetuses, who already had been informed about the situation since prenatal care, and since then was being monitored because of all the uncertainties, fear and insecurities she was going through (...), and with the given assistance, she tried to better deal with such feelings. Test results demonstrated day after day that the babies would have poor chances of survival after birth. The father and grandparents were also followed-up and were badly shaken by the news. A multidisciplinary meeting was held to inform the family about the babies'poor prognosis. The babies died a couple of days after birth. Due to this approach and proper clarification since prenatal care, parents and family members were able to accept the babies'death without much difficulty.” (PSYCH)	“(….) there is a case of this baby who was born just today, with an incompatible with life malformation. The mother went through several services, during prenatal period,which did not clarify her properly about the condition, nor prepare her psychologically. She arrived at the hospital to have the baby without knowing her baby would not be able to survive and without prior psychological preparation for this. A prior preparation by a multidisciplinary team in prenatal care would be ideal to help with loss and grief, right after birth(….)”(PEDRP2)
<b>MULTIDISCIPLINARY ASSISTANCE</b>	“(….) in one case of a baby with poor prognosis, a multidisciplinary meeting was held with professionals from Medicine, Nursing, Psychology, Social Work and Physiotherapy to propose Palliative Care to the family. There was a fantastic approach, psychological and emotional preparation were offered for everyone involved. Parents felt really relieved with Palliative Care and reported relief in suffering (….)” (NEORP3)	“(….)here we have families who are given the diagnosis of a serious fetal abnormality shortly before birth. Even with prenatal care, there are services that do not have a multidisciplinary team that can prepare this family and clarify about the situation, explaining some questions and helping them to make the best decisions before and after birth. Therefore, this pregnant woman had no knowledge about the pathology that affected her child, so the Obstetrics and Neonatology teams, each in their own unique way, separately, were responsible for communicating this to the family(….)”(NEORP2)
<b>DIVERGENCE OF</b>		“(….) a newborn with a poor prognosis who had been hospitalized for 2 months and underwent every treatments and procedures that could be done. It seemed that Medical team, by some heroic motive, wanted to prove to someone

<b>CONDUCTS</b>		that they could save this life at all costs, that this would be by their own merit. They knew from the beginning that this anomaly was very serious and still did not take a moment to considerate that they did not need to perform so many procedures for 2 months, just prolonging suffering for everyone. The baby ended up dying the day after another surgical procedure(...) "(NICURN2)
<b>DELIVERING BAD NEWS</b>	"(...) there was a birth of a newborn whose kidneys were failing and needed dialysis, and for that he had to go through a procedure to make a canal to the bladder, which only made the situation even worse, until a day came when he had several cardiac arrests and needed CPR for 6 times. By the time of doctor's shift-change, the family was called and the doctor explained the whole situation and said that the baby had no favorable prognosis, that there was no longer any chance of improvement, and that performing CPR would only prolong patient's suffering. The promptly family understood. The mother was offered to hold her baby in her arms for the first time while it was still alive, photographs were taken. The baby died the next day." (NICURN3)	"(...) there was a newborn with cerebellar hypoplasia, hydrocephalus and other malformations, he was on invasive mechanical ventilation and underwent several surgical and therapeutic treatments, blood tests, medications (...) until the baby eventually died. The medical team had a frank conversation with the mother about the limitations of survival and the proposal to offer quality of life to the baby only a few days before death. Before that, the family trully believed in a normal evolution of the child after all these procedures performed. She took her baby in her arms only once (...) "(NEORN4)
<b>UNIT'S PHYSICAL STRUCTURE</b>		"(...)whenever a pregnant woman with an early fetal death is hospitalized, we always try to keep her as far away as possible from other pregnant women. Our obstetric Emergency Room physical structure is very limited, usually overcrowded, patients facing each other, and that is very distressing for this mother with intrauterine fetal death to hear about fetal heartbeats from other patients, to hear the care team asking another patient if the baby is moving. In this particular moment of pain, the patient needs privacy, silence and comfort (...) "(OERPNI)
<b>FAMILY'S EMOTIONAL ASPECT</b>		"(...)the birth of a baby who needed ICU admission, led to a lot of concern and anguish in the mother for the loss of the dream of having the baby in her arms, breastfeeding, being together with her child, and due to all the complications, all of those things can take some time or even never happen... The mother suffers from the separation, she suffers from concerns about the clinical condition, they often do not understand everything that is happening, the procedures, the equipment. And the ir also suffering for the baby, in being in an environment of constant stress: excessive light, painful stimuli, noises, in addition to the separation from physical contact with the mother, so, in my opinion, it might be very difficult for the mother to considerate about allowing palliative care." (PHYSIO2)
<b>MULTIDISCIPLINARY TEAM'S EMOTIONAL DISTRESS</b>		"(...)birth of Siamese twins, the family was well aware of the situation and prognosis since prenatal care, but even so they decided to continue the pregnancy. The babies were referred to the NICU right after birth, having completed all the necessary procedures and tests, and just before knowing the results, the father told the doctor on duty that if he needed to give up a baby's life in favor of the life of the other, they would agree. Unfortunately, test results confirmed that both babies were incompatible with life. From there, measures of comfort and analgesia were

		taken. There were moments of pain and anguish for the parents, which reflected in the multidisciplinary team's daily life. There is no psychological support for the professionals to deal with daily adversities(...)" (NICUPN11)
<b>ELIGIBILITY CRITERIA</b>	"(...)a newborn arrived who had been born with several malformations, having no nose, and the medical team decided not to intubate and just provide comfort measures, nutrition through feeding tube, and no invasive procedures. This family already knew about the diagnosis in the prenatal period and was already prepared for this outcome. They waited for the mother to come back from the operating room, she took the baby in her arms, stayed with him for a while, and then the baby died. The father also participated in this moment and could say goodbye to his son in his arms too(...)" (NEORN1)	"(...) a 32-week of gestational age premature infant with Patau syndrome and complex congenital heart disease was hospitalized and remained at the hospital for about 2 months, requiring mechanical ventilation, vasoactive medications, antibiotics. There was numerous discussions with cardiology team about the possibility of cardiac surgery . During this period, everything was tried to "cure". It was only after many multidisciplinary discussions that it was possible to reach a consensus on only taking comfort measures, analgesia, not taking any more tests and only offering basic support. Many doctors find it difficult to accept this kind of approach, therefore they end up prolonging false hopes in the family(...)" (NEO4)
<b>FAMILIES BELIEFS</b>	"(...)there was a day when a baby with a congenital malformation, it was a very severe condition from a therapeutic point of view, there was nothing more to be done and it was progressing to death. Some health care professional asked the parents if they wanted to say a prayer, they accepted. Together, they prayed for the baby, and this was a moment of comfort for the family, easing their suffering at that time(...)" (PHYSIO2)	"(...)we had a case of a newborn with multiple malformations, with a poor prognosis. A planned and long-awaited child ba the parents. Parents had the diagnosis since prenatal care, but they hid it from the rest of the family and had high hopes to be a false diagnosis. After birth, the diagnosis were confirmed and during hospitalization, numerous treatments, procedures, interventions and tests were carried out, which only prolonged baby's suffering. However, the multidisciplinary team had to maintain this curative approach, as the parents did not accept comfort measures or paliative care because they sought an answer in religion and were certain a miracle would happen(...)" (NICUPN11)
<b>FAMILY INSERTION</b>	"(...) we had a birth of Siamese twins, the family was aware of the poor prognosis since prenatal care. After birth, only comfort measures were chosen. The babies were referred to the NICU, and in the few hours of survival, family members were allowed to visit, they hold the babies, took pictures and remained with them until death. The scene that marked me the most was the grandmother with them in her lap, showing videos on her cell phone and singing to them. The family, which initially seemed bewildered, understood the institution of comfort measures without questioning and without any feeling of guilt." (NEORP3)	"(...) ) the family suffers a lot, they cry, they get angry. They need a warm reception, special care and sensitivity from the multidisciplinary team. Hospitalization is often so exhausting and take too long. The team needs to take special care in the daily conduct of the NICU, to welcome, to put yourself in the other's shoes, not laughing out loud, not talking about your personal life. To be a friendly shoulder to cry on when needed, to hug. A daily work for the humanization of the unit, in the presence of the family(...)" (NICUPN6)

Source: Authors.

The present study revealed that the multidisciplinary team involved in PC for pregnant women with detected fetal abnormalities and/or newborn babies with poor prognosis along with their families, regardless of occupation, report a greater number of negative aspects regarding PC. Participants reported negative aspects in all categories analyzed. A systematic review about professionals' perspectives on neonatal PC, identified that the need for training and education about PC is one of the main barriers (Beltran & Hamel, 2020).

In the prenatal category, it was reported that, in face of prenatal diagnosis of life-threatening conditions or poor prognosis, pregnant women and their families are often not properly clarified about the situation, nor are they followed-up during prenatal period. Some participants mentioned the need for a trained multidisciplinary team in PC, responsible for

following up the mother and the rest of the family. Corroborating this finding, a study regarding the barriers doctors and nurses face in Perinatal Palliative Care (PPC) practice concluded that, given the fetal diagnosis of some serious or life-threatening abnormality, this pregnant woman needs to be followed up by a multidisciplinary team specialized in PC. Lack of time to counsel patients in prenatal consultations was also reported as a barrier to PPC (Wool, 2015).

An early care with a multidisciplinary PC team in the prenatal phase makes the prognosis and death acceptance less painful. A retrospective study with family members of patients with a prenatal diagnosis of high mortality conditions reinforces the importance of multidisciplinary and the creation of an approach structure where it is possible to talk about the disease, provide support, respect values, develop care plans, besides an adequate follow-up after birth (Bernardes et al., 2020). Therefore, it is extremely necessary to form a structured PPC program for better management (Flaig et al., 2019).

Multidisciplinary care, when properly planned in meetings that provide equal voice and actions to all professional categories, is considered as a facilitator for PC. Welcoming the families of babies eligible for PC and clarifying their doubts are essential for acceptance of this type of assistance, and also favor suffering relief, not only for family members but also for professional involved, improving quality of life for these babies, even if briefly (Beltran & Hamel, 2020) (Cortezzo et al., 2014).

The diagnosis of a severe fetal abnormality usually is revealed close to birth and, in the absence of a cohesive and trained multidisciplinary team, the family receives a lot of divergent information from different health care professionals. This raises awareness for the necessity of a multidisciplinary team specialized in Neonatal Palliative Care (NPC). A study, in which a questionnaire was applied to neonatologists and pediatric intensivists, showed that among the barriers around PC management in intensive care units, insufficient knowledge on the subject and lack of a multidisciplinary PC team were the main obstacles for appropriate practice (Hajery et al., 2018).

In the Divergence of Conducts category, therapeutic obstinance and constant changes in therapeutic approaches by the medical team were considered a hindrance for adequate PC practice. Therapeutic obstinance is already pointed out by some authors as one of the first problems for PPC implementation, as well as poor interdisciplinary communication and cooperation, lack of guidelines and absence of training programs for health care team. Thus, there are numerous challenges to overcome in order to unify and make the conducts in PC more cohesive (Tosello et al., 2015) (Quinn & Gephart, 2016) (Feltman et al., 2012).

In our study, participants reported difficulty in delivering bad news, which can delay important conversations about chances of survival and postpone measures to offer comfort and quality of life at this critical moment. The lack of adequate education and training generates non-empathic, brief and iatrogenic communication (Lima et al., 2019). A study with professionals in the area of medicine and nursing at a neonatal and pediatric ICU in Southern Brazil demonstrates that sincerity, bonding and empathetic approach are crucial elements during communication (Koch et al., 2017).

Delivering bad news properly, in a sincere, clarifying and empathetic way, can provide quality of life for all people involved in PC. After the conversation and proposal for PC, offering parents the opportunity to do some of the same care they would do at home for their baby can represent significant and memorable moments for the family. Breaking bad news is a frequent and common task in high-risk obstetric hospitals and clinics. A study performed in São Paulo evaluated the impact of delivering bad news training, according to the perception of a team of specialists in maternal-fetal health, and showed a positive impact on PC practice (Oliveira et al., 2020).

An inadequate physical structure, with absence of individual and private beds, worsens the difficult moment of pain and grief and also impairs the comfort and privacy of these families. Some authors indicate that an inadequate physical environment, whether for grieving or greater privacy for families, is an important limitation for PPN and NPC (Kilcullen, 2017) (Kyc et al., 2020).

In the present study, health care professionals declared that family emotional distress is an important issue in PC practice. The birth of a baby with severe abnormalities and/or limited chances of survival causes a loss a family's expectations, anxiety and doubts about clinical picture and evolution, in addition, the baby's own physical suffering during hospitalization might cause severe emotional distress in family members. According to a study involving nursing experiences in a NICU, professional recognize aggravation on family's emotional distress especially in moments such as baby's clinical worsening and death, which is predictable since they face situations of loss at a time in life usually marked by celebrations (Almeida et al., 2016).

The multidisciplinary team emotional distress was frequently reported in cases eligible for PC. The pain and anguish of parents reflect directly on the professionals' daily life, who mostly do not have psychological support to deal with such daily adversities. Another study demonstrates that neonatologists and pediatric intensivists experience difficulty in managing PC due to emotional exhaustion (Hajery et al., 2018). In addition, a systematic review and another study about neonatal nurses experiences showed that professionals in transition from curative to palliative care might present sadness and an inner feeling that they are not doing enough for the patient (Lewis & Ahern, 2017) (Gibson et al., 2018). The establishment of institutional policies focused on taking care of the health professional proves to be important and serves as supportive for teamwork. Professional group discussions regarding cases of PC, where they can share their experiences, can help alleviate anxiety and sadness (Oliveira et al., 2018)(Erikson & Davies, 2017).

In the Eligibility Criteria category, delays and difficulties in starting the palliative approach in cases of children with severe abnormalities and limited survival chances were related by the team. This fact might be related to the lack of trained professionals for such approach, which consequently brings some enlightenment about eligibility criteria for NPC and when to start it, causing divergences within the multidisciplinary team. A study regarding guidelines for end-of-life care in America showed that institutions need better education and training in PC so health care professionals can have these eligibility criteria well-established (Haug et al., 2018).

When eligibility criteria for PC are well-established and the family has already had proper clarification about the diagnosis and limited chances of survival, the multidisciplinary team is able to provide for both the baby and the family a dignified farewell. Therefore, the development of guidelines for NPC with concise eligibility criteria is crucial (Gibson et al., 2018).

Family beliefs are factors that can directly impact palliative care. Some parents, despite being well informed since prenatal period about diagnosis, severity and poor prognosis, end up not accepting the information and reject a palliative approach after birth, which leads to useless treatments that will only prolong the baby's suffering. The non-acceptance phase of such diagnosis and consequent need for parents to request numerous interventions is already addressed in other studies, which report that some parents keep asking the multidisciplinary team for interventions that goes beyond what they consider appropriate, using technological support to maintain the baby's life at all costs even if there is no apparent quality of life (Kyc et al., 2020).

On the other hand, family beliefs are important in a way that families can go through this difficult process more smoothly. A qualitative study that assessed physicians' perceptions of religiosity/spirituality on end-of-life pediatric care reported that, for most professionals, religiosity played an important role in their medical practice especially during communication with parents. Some doctors used their own religious beliefs to support families, help them to maintain hope, participate in prayers and even alleviate their own suffering from the loss of their patients (Bateman et al., 2019).

In this study, family insertion in PC was perceived as a barrier. Some professionals classified as overwhelming having to deal with the families' grief and suffering at the same time of supervising the multidisciplinary team so they do not present any unintentional behaviors that might disrespect or aggravate the situation, which indicates a daily work for professionals

humanization. Other studies about professional's perception of PC also reported that sometimes the parents' presence in the unit was distressing, especially when they arise strong emotions in the team or ask questions that they do not have an answer to (Oliveira et al., 2018) (Almeida & Moraes, 2016).

Family insertion since prenatal phase in cases of babies eligible for PC was also mentioned as important, as family members who are well informed about the condition and participate along with the multidisciplinary team in the decision-making can considerably favor PC practice. In daily practice, decision-making involves the opinions of multidisciplinary team almost entirely, with little family's collaboration to decide together what is the best approach for the moment. However, it is necessary for this situation to change and for the family's participation to be expanded. In order for this to happen, an adequate communication between the medical team and the parents is important (Beltran & Hamel, 2020) (Richards et al., 2018) (Kenner et al., 2015).

A study entitled "The parents' voice" on indicators of parental satisfaction and quality of PC in perinatal period confirms the strong desire of parents to have their children treated with dignity and respect. Parents need to be respectfully informed about prognosis, to have the option of performing any possible care and to be supported in any cultural or religious ritual they consider significant (Wool et al., 2016).

#### **Study limitations**

The limitation of this study is related to professionals' memories in relation to their experience involving PC that could not be as vivid, especially if these moments occurred in a period far from the time of data collection. However, some of these experiences are very striking facts in the professionals' lives and hard to forget.

#### **4. Conclusion**

PC in Perinatology and Neonatology is recent topic that generates numerous mixed feelings and different opinions. In this study, it was possible to identify a more significant number of negative references to the detriment of positive ones regarding PC, demonstrating that such approach involves more difficulties for its proper implementation.

This study provided information that might enable the development of measures to improve the care of pregnant women with detected fetal abnormalities and/or newborns with limited chances of survival, in addition to give adequate attention and emotional support for their families or caregivers, as well as to promote a PPC and NPC group implementation in this service, with periodic training and education for the multidisciplinary team.

More studies about PC practice are necessary as well as to raise awareness of the importance of the topic to other maternal-child units from other institutions, involving the whole multidisciplinary team and not only physicians and nurses, so in the near future new PPC and NPC groups are implemented.

#### **References**

- Almeida, F. D. A., & Moraes, M. S. De. (2016). Cuidando do neonato que está morrendo e sua família: vivências do enfermeiro de terapia intensiva neonatal. *Revista Da Escola de Enfermagem Da USP*, 50(spe), 122–129.
- Almeida, F. de A., de Moraes, M. S., Cunha, M. L. da R., & Baldoino, A. S. (2016). Taking care of the newborn dying and their families: Nurses' experiences of neonatal intensive care. *Revista Da Escola de Enfermagem*, 50(Specialissue), 118–124. <https://doi.org/10.1590/S0080-623420160000300018>
- Bateman, L. B., Clair, J. M., Inquiry, N., Bateman, L. B., & Clair, J. M. (2019). *Physician Religion and End – of – Life Pediatric Care : A Qualitative Examination of Physicians ' Perspectives Physician Religion and End – of – Life Pediatric Care : A Qualitative Examination of Physicians ' Perspectives*. 5(3), 251–269.
- Beltran, S. J., & Hamel, M. N. (2020). Caring for Dying Infants: A Systematic Review of Healthcare Providers' Perspectives of Neonatal Palliative Care. *American Journal of Hospice and Palliative Medicine*. <https://doi.org/10.1177/1049909120965949>
- Bernardes, L. S., Jesus, R. C. D. A., Oliveira, F. F., Benute, G. R. G., Gibelli, M. A. B. C., Nascimento, N. B., ... Francisco, R. P. (2020). Family Conferences

- in Prenatal Palliative Care. *Journal of Palliative Medicine*, 23(10), 1349–1356. <https://doi.org/10.1089/jpm.2019.0579>
- Cortezzo, D. E., Sanders, M. R., Brownell, E. A., & Moss, K. (2014). End-of-Life Care in the Neonatal Intensive Care Unit: Experiences of Staff and Parents. *American Journal of Perinatology*, 32(8), 713–723. <https://doi.org/10.1055/s-0034-1395475>
- Currie, E. R., Christian, B. J., Hinds, P. S., Perna, S. J., Robinson, C., Day, S., & Meneses, K. (2016). Parent Perspectives of Neonatal Intensive Care at the End-of-Life. *Journal of Pediatric Nursing*, 31(5), 478–489. <https://doi.org/10.1016/j.pedn.2016.03.023>
- Da Silva, G. D., Silvino, Z. R., Dos Santos, M. F. de O., Dias, P. S. C., Dela Coleta, M. F., & Matos, P. B. de C. (2016). Técnica de Incidentes Críticos: Aplicabilidade nas Pesquisas de Enfermagem Critical incident technique: applicability in nursing research. *Revista de Pesquisa: Cuidado é Fundamental Online*, 8(2), 4142. <https://doi.org/10.9789/2175-5361.2016.v8i2.4142-4153>
- Erikson, A., & Davies, B. (2017). Maintaining Integrity: How Nurses Navigate Boundaries in Pediatric Palliative Care. *Journal of Pediatric Nursing*, 35, 42–49. <https://doi.org/10.1016/j.pedn.2017.02.031>
- Feltman, D. M., Du, H., & Leuthner, S. R. (2012). Survey of neonatologists attitudes toward limiting life-sustaining treatments in the neonatal intensive care unit. *Journal of Perinatology*, 32(11), 886–892. <https://doi.org/10.1038/jp.2011.186>
- Figueredo, C. (n.d.). *Concepções da equipe multiprofissional sobre a implementação dos cuidados paliativos na unidade de terapia intensiva Perceptions of the multi-professional team on the implementation of palliative care in intensive care units*. 2597–2604.
- Flaig, F., Lotz, J. D., Knochel, K., Borasio, G. D., Führer, M., & Hein, K. (2019). Perinatal Palliative Care: A qualitative study evaluating the perspectives of pregnancy counselors. *Palliative Medicine*, 33(6), 704–711. <https://doi.org/10.1177/0269216319834225>
- Flanagan, J. (1973). A técnica do incidente crítico. *Arquivos Brasileiros de Psicologia Aplicada*, 25(2), 99–141.
- Gibson, K., Hofmeyer, A., & Warland, J. (2018). Nurses Providing End-of-Life Care for Infants and Their Families in the NICU: A Review of the Literature. *Advances in Neonatal Care*, 18(6), 471–479. <https://doi.org/10.1097/ANC.0000000000000533>
- Gomes, B., Calanzani, N., Curiale, V., McCrone P., P., Higginson, I. J., & Brito, M. de. (2016). Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Sao Paulo Medical Journal*, 134(1), 93. <https://doi.org/10.1590/1516-3180.20161341T2>
- Hajery M, A., Mutairi H, A., A, A., & MK, A. (2018). Perception, Knowledge and Barriers to End of Life Palliative Care among Neonatal and Pediatric Intensive Care Physicians. *Journal of Palliative Care & Medicine*, 08(01). <https://doi.org/10.4172/2165-7386.1000326>
- Haug, S., Farooqi, S., Wilson, C. G., Hopper, A., Oei, G., & Carter, B. (2018). Survey on Neonatal End-of-Life Comfort Care Guidelines Across America. *Journal of Pain and Symptom Management*, 55(3), 979-984.e2. <https://doi.org/10.1016/j.jpainsymman.2017.10.023>
- Kenner, C., Press, J., & Ryan, D. (2015). Recommendations for palliative and bereavement care in the NICU : a family-centered integrative approach. *Journal of Perinatology*, 35(S1), S19–S23. <https://doi.org/10.1038/jp.2015.145>
- Kilcullen, M. (2017). *Palliative care in the neonatal unit : neonatal nursing staff perceptions of facilitators and barriers in a regional tertiary nursery*. 1–12. <https://doi.org/10.1186/s12904-017-0202-3>
- Koch, C. L., Rosa, A. B., & Bedin, S. C. (2017). *Más notícias : significados atribuídos na prática assistencial neonatal / pediátrica*. 25(3), 577–584.
- Kyc, S. J., Bruno, C. J., Shabanova, V., & Montgomery, A. M. (2020). Perceptions of neonatal palliative care: Similarities and differences between medical and nursing staff in a level IV neonatal intensive care unit. *Journal of Palliative Medicine*, 23(5), 662–669. <https://doi.org/10.1089/jpm.2019.0523>
- Lewis, S. L., & Ahem, K. (2017). Exploring NICU Nurses’ Affective Responses to End-of-Life Care. *Advances in Neonatal Care*, 17(2), 96–105. <https://doi.org/10.1097/ANC.0000000000000355>
- Lima, K. M. de A., Maia, A. H. N., & Nascimento, I. R. C. do. (2019). Comunicação de más notícias em cuidados paliativos na oncopediatria. *Revista Bioética*, 27(4), 719–727. <https://doi.org/10.1590/1983-80422019274355>
- Oliveira, F. D. C. De, Cleveland, L. M., Darilek, U., Regina, A., Silva, B., & Carmona, E. V. (2018). *Brazilian Neonatal Nurses’ Palliative Care Experiences*. 32(4), 3–10. <https://doi.org/10.1097/JPN.0000000000000361>
- Oliveira, F. F., Benute, G. R. G., Gibelli, M. A. B., Nascimento, N. B., Barbosa, T. V. A., Bolibio, R., ... Bernardes, L. S. (2020). Breaking Bad News: A Study on Formal Training in a High-Risk Obstetrics Setting. *Palliative Medicine Reports*, 1(1), 50–57. <https://doi.org/10.1089/pmr.2020.0014>
- Quinn, M., & Gephart, S. (2016). Evidence for implementation strategies to provide palliative care in the neonatal intensive care unit. *Advances in Neonatal Care*, 16(6), 430–438. <https://doi.org/10.1097/ANC.0000000000000354>
- Radbruch, L., De Lima, L., Knaut, F., Wenk, R., Ali, Z., Bhatnagar, S., ... Pastrana, T. (2020). Redefining Palliative Care—A New Consensus-Based Definition. *Journal of Pain and Symptom Management*, 60(4), 754–764. <https://doi.org/10.1016/j.jpainsymman.2020.04.027>
- Richards, C. A., Starks, H., O’Connor, M. R., Bourget, E., Hays, R. M., & Doorenbos, A. Z. (2018). Physicians Perceptions of Shared Decision-Making in Neonatal and Pediatric Critical Care. *American Journal of Hospice and Palliative Medicine*, 35(4), 669–676. <https://doi.org/10.1177/1049909117734843>
- Tosello, B., Dany, L., Bétrémieux, P., Le Coz, P., Auquier, P., Gire, C., & Einaudi, M. A. (2015). Barriers in referring neonatal patients to perinatal palliative care: A French multicenter survey. *PLoS ONE*, 10(5), 1–11. <https://doi.org/10.1371/journal.pone.0126861>
- Wool, C. (n.d.). *Barriers in perinatal palliative care*. (February 2015).
- Wool, C., Black, B. P., & Woods, A. B. N. (2016). Quality indicators and parental satisfaction with perinatal palliative care in the intrapartum setting after diagnosis of a life-limiting fetal condition. *Advances in Nursing Science*, 39(4), 346–357. <https://doi.org/10.1097/ANS.0000000000000147>