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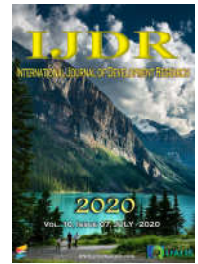
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## PALLIATIVE CARE IN A NEONATAL INTENSIVE CARE UNIT: A SYSTEMATIC REVIEW

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### ABSTRACT

Palliative Care in a neonatal intensive care unit represents an expanding area that needs special attention in comprehensive care for the newborn and family during treatment and the period of mourning. This study aims to identify the Palliative Care actions performed in a neonatal ICU. This is a systematic review, which followed the recommendations of the Cochrane Collaboration. The search bases included: MEDLINE, Cochrane Library and Scielo. With the application of inclusion and exclusion criteria, 10 articles were selected. The analysis of the protocols revealed that there are measures in common between them, such as the use of comfort measures, support to the family during the hospitalization process and in mourning, discussion with the family and shared decision, interaction of the multidisciplinary team, withdrawal from intensive means life support and continued team training. The evidence points that the implementation of the Palliative Care program in NICU is beneficial to the patient, family and team, but there are fundamental approaches that need to be addressed by protocols to be implemented and that there is still a need to improve specific points such as communication between family and team and there is a lack of care with emotional health and perceptions of professionals.

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## INTRODUCTION

The palliative care provision, and the term "hospice" (from the same linguistic root of hospitality) have their origins in the medieval times, when people referred to a place of shelter and rest for tired or sick travelers on a long journey. It was first used in the specialized care to terminal patients by the physician Cicely Saunders, who began her work in 1948 and ended up creating the first modern hospice, St. Christopher's Hospice, in a residential suburb in London, initiating the whole movement that spread to other countries in the following years. Saunders, during a visit to Yale University in 1963, introduced the idea of specialized care in the United States for the severely ill patients who had no chance of survival. Her lecture, given to medical students, nurses, social workers, and chaplains on the concept of holistic Palliative Care, included pictures of end-stage cancer patients and their families, showing dramatic differences before and after symptom control (Saunders, 2001).

The word "palliative" comes from the Latin word *pallium*, which means cloth or mantle that covers, hides. It is also used metaphorically as cover up, disguise. Nevertheless, in the medical area, Palliative Care does not serve to cover up or disguise, but instead to protect. Palliative Care is a set of measures that shall be provided by a multidisciplinary team, and aims to improve the quality of life of a sick person and their relatives, alleviating and preventing suffering in the face of a severe illness that may end their life. Palliative Care is often optimally provided, along with care for extending life, with a coordinated approach, thus presenting itself as a mutually exclusive alternative in an integral component of critical patient care from the time of ICU admission (Carter *et al.*, 2017). They were considered by the World Health Organization (WHO), in a humanitarian and global way, as an urgent need for people with severe, incurable diseases. The 67<sup>th</sup> World Health Assembly Resolution of May 2014 recommended the integration of Palliative Care to all health settings for all member countries (WHO, 2002).

In Brazil, Palliative Care is first reported in the 1980s, in the South and Southeast regions, but it was only in 1998 that a unit exclusively dedicated to this kind of care was created in the Hospital of the National Cancer Institute in Rio de Janeiro (Figueiredo, 2011). In that same year, Palliative Care was standardized through Ordinance no. 3535/98, which carried out the registration of all the institutions that worked with Palliative Care in oncology; in 2002, Ordinance No. 19, dated January 3, 2002, was issued which inserted the National Program of Assistance to Pain and Palliative Care in the Unified Health System (SUS). Ordinance No. 1, dated July 23, 2002, created the Reference Centers for Pain Management at SUS, and Ordinance No. 881, of July 19, 2001, instituted the National Program for Humanization of Hospital Care, giving subsidies to the implementation of Palliative Care services in the country (Iglesias *et al.*, 2016). In order to insert the concept in a technically correct way, aiming at the expansion of Palliative Care in Brazil, in 2006 the Federal Council of Medicine (CFM) published Resolution No. 1805/2006 regulating orthothanasia with the consent of the patient or his/her legal representative. Then, intense discussions began to emerge, and the subject began to gain prominence until, in 2009, the new Code of Medical Ethics included Palliative Care in different chapters as a medical act, and determined that it should be carried out in appropriate clinical situations. Subsequently, in 2011, palliative medicine was promoted to an area of practice, in addition to oncology, such as geriatrics, pediatrics and intensive care medicine. In 2012, CFM recognized the patient's autonomy regarding their decisions in the terminal stage of the disease, based on the living will as a guiding instrument that facilitates communication among patients, family and professionals. In 2016, the need to stimulate the development of Palliative Care units was recognized to refer non-eligible patients with clinical conditions of disease irreversibility to the Intensive Care Unit (ICU) (Fonseca *et al.*, 2017).

Pediatric palliative medicine is a field of medical sciences aimed at alleviating suffering, improving quality of life, facilitating shared decision-making and coordination of care for severely ill children and their families. Palliative Care is appropriate since the critical diagnosis is made, regardless of the certainty of prognosis, and may accompany life-prolonging therapy (Moore *et al.*, 2014). This pediatric care is appropriate for any child with potential limiting illness, and is not restricted to the end of life and to bereavement. It is often provided concomitantly with curative therapy. Documented benefits include symptom management, perceived quality of life, and better communication. Neonatal Palliative Care advocates the prevention and relief of physical, emotional, social and spiritual pain and suffering, and is started with curative measures and prolonged after death including the bereavement process. However, the integration of Palliative Care in NICU services is controversial and is hampered by a number of factors, such as prognosis uncertainty, attempts to overuse technological and scientific resources in medical practices, fear of possible legal consequences, understanding of death as a failure by professionals of the team that do not see death as a natural process, as well as parents who, being sensitive, overlap the risk of loss of life with their demands and expectations (Soares *et al.*, 2013). Although there are records of neonatal Palliative Care protocols, their use is small. The main focus of existing programs is almost exclusively on terminality and death, with no integration with measures to extend life, advanced care planning, management of neonates'

comfort status, and psychological support to parents and professionals (Parravicini, 2017). The practice of neonatal Palliative Care continues to evolve, increasing the number of publications assessing the impact of such care on families and on the patient's quality of life, either globally or by analyzing specific points such as team-family communication, bereavement support, discontinuation of intensive means of life support, and exploring the view by health professionals. Despite this, there are few Brazilian studies due to the small number of Palliative Care programs in neonatal ICUs offered in hospitals in Brazil. This review aims to identify the actions provided for in the protocols of Palliative Care in neonatal ICUs, highlighting the benefits of the practices performed, detailing the approaches and indicating the points that need improvement. This research aims to serve as a tool to expand the debate in this area, to help the implementation of new services improving the care of these extremely vulnerable patients.

## METHODS

A systematic review of the literature was carried out in accordance with the recommendations of the Cochrane Collaboration and PRISMA (Preferred Reporting Items for Systematic Review and Meta-analysis Statement) (Moheret *et al.*, 2015) to identify the actions of Palliative Care performed in a neonatal ICU. This systematic review was submitted to the PROSPERO platform, with identification number CRD42019125912. PVO strategy (an adaptation of the PICO technique), which represents the acronym for P: problem situation, participants, context; V: study variables; O: outcome or result (Biruelet *et al.*, 2011), was used to formulate the guiding question defined as: "What are the actions of Palliative Care performed in neonatal ICUs?". The studies were identified by searches in the following electronic databases: MEDLINE (via PubMed), The Cochrane Library and Scielo. The descriptors used were: "palliative care", "neonatal intensive care unit" and "neonatal ICU", combined by the "AND" Boolean operators. The terms chosen for search were consulted and listed as descriptors in *MeSH*, a controlled vocabulary of the US National Library of Medicine that gives uniformity and consistency to the biomedical literature indexing and cataloging.

The identification code of "palliative care" is D010166, and the synonyms "neonatal intensive care unit" and "neonatal ICU" is D007363. The term "protocol" was not included in the search because it is not a descriptor. The studies published in the period from January 2014 to December 2018 were considered. The search strategy used in each database is represented in Table 1. The original articles with complete texts, published in Portuguese, English and/or Spanish and that answered the research question were considered as inclusion criteria. The exclusion criteria were duplicate articles and studies with Palliative Care protocols or actions not used in neonatal ICU. At the end of the literature searches, these criteria were applied, followed by the analyses of titles and abstracts for data collection and evaluation. After this, the complete articles were evaluated by two independent researchers to extract the relevant information, identify and analyze the actions of Palliative Care performed in neonatal ICUs. A qualitative analysis of this information was carried out, comparing the results found with each other and with data from the literature.

## RESULTS AND DISCUSSION

The results of the search for the studies published in the databases using the selected descriptors started with 46 articles and after the application of the inclusion and exclusion criteria, 10 articles related to the research objective were selected. Figure 1 shows the flowchart with the selection steps of the articles.

Care services for newborns, which began in the 1980s, when *hospice* principles were being disseminated in the United States. Table 2 provides the general information about the selected studies, identifying them. Three studies, all published in 2015 (Petteyset *al.*, 2015; Samsel *al.*, 2015; Youngeet *al.*, 2015), had a comparison of services provided before and after the implementation of the palliative care program. The results obtained from the change in the treatment of patients and their families were significant, indicating better management of



Source: Author, 2019

Figure 1. Flowchart of article selection

Table 1. Search strategy used in the different databases consulted

Database	Search strategy
MEDLINE (via PubMed)	Advanced search: # 1 (palliative care [Title/Abstract] AND neonatal intensive care unit [Title/Abstract]) OR # 2 (palliative care [Title/Abstract] AND neonatal intensive care unit [Title/Abstract]) OR
The Cochrane Library	Advanced search: # 1 (palliative care AND neonatal intensive care unit): ti, ab, kw # 2 (palliative care AND neonatal ICU): ti, ab, kw
Scielo	All indexes: # 1 (palliative care) AND (neonatal intensive care unit) # 2 (palliative care) AND (neonatal ICU)

Source: Author, 2019

The first analysis of these articles shows that there were more publications between 2015 and 2016, with three and five studies published respectively, and only one article in 2017 and one in 2018, which indicates an apparent reduction in the conduction of original research on actions of protocols used in Palliative Care. The perception of reduction may also have been triggered by a change in the pattern of the keywords used to identify the articles. The distribution of the articles in the countries where the research was carried out was limited to the Americas, Europe and Oceania, with no Asian or African publication found, and the numerical relationship showed a greater concentration in North America, mainly in the United States, with six publications. In addition to these publications, there was a work from New Zealand, one from Brazil, one from Canada and one from England. The numbers found reflect the US concern about the implementation of Palliative

symptoms and pain, more effective communication and sharing with families, more natural death, and greater satisfaction with the service. Despite a number of improvements, it was emphasized that patient/family-centered care could be improved. The results of (Petteyset *al.*, 2., 20115) showed greater satisfaction among families receiving care, and reduced stress levels, possibly promoted by comprehensive care to families through meetings and a psychological support program, corroborating the literature that highlights the following benefits from the implementation of the Palliative Care program in neonatal ICUs: better control and relief of symptoms compared to usual curative care, cost reduction with better use of health resources (Mcateeret *al.*, 2013), excellence in communication between professionals and family, discussion of goals and advanced planning care, appropriate end-of-life support, psychological support for

Table 2. Identification of the selected articles

ID	TITLE	AUTHORS	DATE	COUNTRY	PLACE OF STUDY
1	Palliative care in a tertiary neonatal intensive care unit: a 10-year review.	NG, et al.	2018	New Zealand	Tertiary NICU of Wellington Regional Hospital
2	Análise dos óbitos e Cuidados Paliativos em uma unidade de terapia intensiva neonatal.	MARÇOLA, et al.	2017	Brazil	Hospital de Clínicas of the Medical School of the University of São Paulo
3	Perceptions of palliative care in the NICU.	FALCK, et al.	2016	United States	Medical School of the University of Maryland
4	A descriptive report of end-of-life care practices occurring in two neonatal intensive care units.	LAM, et al.	2016	Canada	Two tertiary NICUs, affiliated with the University of Alberta
5	Primary palliative care in neonatal intensive care.	MARC-AURELE & ENGLISH	2016	United States	University of California
6	Parental involvement in neonatal critical care decision-making.	SHAW, et al.	2016	England	NICU in England (Not specified)
7	Palliative care in neonatal intensive care, effects on parent stress and satisfaction: a feasibility study.	PETTEYS, et al.	2015	United States	Tertiary NICU Hospital in California with Pediatric Palliative Care Program established
8	End-of-life care in a regional level IV neonatal intensive care unit after implementation of a palliative care initiative.	SAMSEL & LECHNER	2015	United States	Level IVNICU of <i>Women and Infants</i> Providence Hospital
9	Impact of a palliative care program on end-of-life care in a neonatal intensive care unit.	YOUNGE, et al.	2015	United States	NICU at Duke University Medical Center
10	End-of-life care in the neonatal intensive care unit: experiences of staff and parents	CORTEZZO, et al.	2015	United States	Connecticut Children's Medical Center's NICU

Source: Author, 2019

families including decision-making for critically ill patients (Manjii *et al.*, 2011; Pippa, 2017). The use of comfort measures was cited in all compiled articles, showing the importance of their conscious use, as it aims to improve the patient's quality of life, and is one of the pillars of the Palliative Care precepts. The outcomes of Samsel&Lechner (2015) and Younge (2015) pointed to better use of drugs to provide comfort to patients after the implementation of a Palliative Care program, which establishes stricter guidelines for their use. Accordingly, the Brazilian study by Marçola *et al.* (2017) found inefficient use of drugs to control pain in patients who were not on Palliative Care, reflecting the lack of professional training, or patient undervaluation. Effective pain management may be performed through pharmacological therapy, as cited by four articles in this research, through the use of opioids, sedative and anxiolytic, non-steroidal anti-inflammatory drugs, dexmedetomidine, propofol and gabapentin (Carter and Brunkhorst, 2017). Only the article by Marc-Aurele& English (2016) mentioned the use of non-pharmacological pain control measures commonly used for mild and moderate pain, including the kangaroo method, skin-to-skin care, non-nutritive sucking, breastfeeding, and massage. Integrative medicine therapies such as music therapy and therapeutic healing or touch could also play a role in symptom control. In a randomized music therapy study for 272 neonates, the use of this technique led to a significant increase in positive infant sleep patterns, as well as a decrease in parental stress (Loewy *et al.*, 2013).

It is necessary to consider the parents' desire for a special end of life, to perform rituals or spiritual practices such as blessings and baptisms, and respect cultural preferences allowing the health team to adapt interventions. A recent trend is the availability of a cradle-based refrigeration system that allows the deceased baby to stay with the parents for a longer period (2018). As in the findings by Falck *et al.* (2016) and Lam *et al.* (2016), families reported the importance of physical representations of the newborns who died, supporting bereavement programs that allow families to create and collect physical representations of their children. According to the outcome of Cortezzo *et al.* (2015) lack of privacy in a

traditional open NICU model impacts emotional space, family bonding, and communication of confidential medical information. There is evidence of adverse effects on the NICU patient's neurodevelopment with this conformation, as patients are exposed to physiological stressors. In addition, family-centered care is challenged by physical limitations in this space. Thus, the single-family room is considered by many specialists as a standard of care, and its advantages include better family-centered care, higher breastfeeding rates, increased privacy, and increased parental satisfaction with care (Stevens, 2015; Swanson *et al.*, 2013). In contrast, several parents emphasized how other families in the NICU were a great source of support for them as they understand the situation they are facing. These families provided empathic support and friendship that often goes beyond hospitalization (Currie *et al.*, 2016). In eight of the ten articles, moments of discussion with families are recommended, including the definition of change in the type of treatment, dressing for palliative care, discontinuation of intensive life support or non-cardiac resuscitation. These moments also make up family-centered care. Communication between the team and the family is the centerpiece in establishing mutual trust, facilitating the understanding of the situation and resulting in the selection of the best option for the patient. Early integration of Palliative Care enables significant involvement in the support to decision for families and physicians. The main focus is the maximization of the quality of life of patients and families through the disease. Integrating this focus early can help families when they begin formulating their quality-of-life goals. As the results obtained by Marc-Aurele& English (Marc-Aurele and English, 2016) showed that neonatal ICU professionals should improve their listening and communication skills, even if they are not consultative professionals in Palliative Care, which would be important for the implementation of an integrated quality model. In their research, Shaw *et al.* (2016) analyze conversations between family and physicians when decision-making becomes necessary. Two different approaches were used by the teams, one where the professional exposes the patient's condition and recommends what would be the best behavior in their view. In the second approach, the professional explains the clinical

situation and presents possible options, while the family says what they think is best at that time. This strategy allowed greater understanding between the team and the family, reaching a common sense of the behavior to be taken. Respect for the family's opinion and beliefs was also higher, which led to greater acceptance of the patient's actual clinical picture. In one of the conversations, when the professional used the recommendation communication technique, the patient's mother repeated the same question several times: "Are you suggesting I kill my son?" This reflects the need for a considerable investment in staff training to better communicate with the family. The neonatal ICU staff masters points of interaction with the families, but relegate psychosocial concerns that may inform value-based preferences. Team members acknowledge their inexperience in end-of-life communication, as well as transitions in Palliative Care. Advanced communication training may decrease dissatisfaction and may improve ICU suffering (Meert *et al.*, 2008; Madden *et al.*, 2015). The shared decision is intrinsically linked to the discontinuation of intensive life support, mentioned by four studies, and the limitation of resuscitation techniques, which are one of the measures used in palliative care. Nevertheless, the literature points to short-term outcomes of the treatment limitation discussions for neonates, showing that a considerable portion of families chooses to keep full intensive care even after meetings (James *et al.*, 2017).

Lam *et al.* (2016) analyzed the deaths recorded in medical records between January 2009 and December 2013, confirming that most deaths occurred after the elective interruption of intensive life support (mainly including mechanical ventilation) decided in meetings with counseling regarding the anticipated outcome of poor development or perceived quality of life, or the situation of a clinically deteriorated neonate despite treatment. The subject of communication brings the importance of the preparation of the team, which shall support each other and agree on the actions taken during patients' treatment. In the article by Falck *et al.* (2016) team professionals reported feeling greater confidence when providing care to several newborns in the same room and with the rest of the team in the same place, facilitating the exchange of information and the assistance of colleagues when needed. In addition, one of the mainstays of Palliative Care is the multidisciplinary team of professionals, who need to interact accordingly from the implementation of the programs to the provision of service to the patients and their families. Despite the benefits of a multidisciplinary team for patients and their families, the programs give little emotional support to health professionals who live in a confined and stressful environment. Cortezzo *et al.* (2015) found that almost 70% of respondents (physicians, nurses and assistants) provided emotional support to their own staff, and nearly 51% attended *debriefing* meetings with their peers; however, in the statements collected, a nurse commented that she would like more teamwork and greater communication among calls and group members. Another important point to consider is the continuing education of the team of professionals (cited by two articles), but only the guidelines for the implementation of the protocol in Samsel & Lechner (2015) explicitly encourage constant training. At the beginning of the program, a conference on Neonatal Palliative Care was launched, directed to the entire pediatric department of the Hospital, which aimed to educate professionals about current Palliative Care and perinatal and neonatal end-of-life. The conference was held jointly by a local neonatologist and an external pediatric

Palliative Care specialist. Other educational interventions included smaller neonatal Palliative Care conferences for NICU residents and nursing staff, and an online learning module was available to review conference material. It is interesting to note that although the subjects covered were mentioned in several articles of this research, the work by Ng *et al.* (2018) defended two aspects that were different from the others. The first is about the record of activities carried out within the NICU Palliative Care program, from clinical procedures to *debriefing* meetings or shared decision making with the family. These records allow the analysis of variables over time, measuring program efficiency in patient progression, symptom management, pain control, death data, communication with the family, and facilitate information exchange when there is a change of teams on certain shifts. The other aspect defended in the article is the implementation of an NICU Palliative Care service in the integrative model, especially for preterm neonates or those with other complex comorbidities where the notion of Palliative Care is presented along with curative measures. This would ensure that families were involved in the planning of care, whose clinical progression and decision-making is updated. This care model allows frank discussions with families, including critical diagnoses. In all the articles analyzed it is possible to find peculiarities in the Palliative Care guidelines, but in general all address the control of symptoms, pain control, relationship with the family in which communications of the patients' clinical condition, their prognosis, shared decisions about discontinuation or maintenance of intensive life support, resuscitation procedure, *debriefing* meetings, and in case of loss, bereavement support, are inserted, always respecting the family's culture and spirituality, the need to register actions, and the importance of educational and emotional support to the multidisciplinary team of professionals. There is still a need for service improvement in many respects and, for this, research becomes important as it reveals points to be improved. The synthesis of the articles reveals that despite failures, services are following WHO recommendations, and shows an increasing need and the benefits of implementing a structured Palliative Care program in neonatal ICUs.

## Conclusions

This research shows that there were more articles published in 2015 and 2016 than in the last two years, and that North America, especially the United States, published half of the related articles, exploring the topic more than other countries. In the analyzed studies, the following commonly practiced actions are recommended by WHO: (1) care is centered on the family and the patient, considering the holistic aspects for continuity of treatment, valuing the patient's quality of life; (2) holding family meetings to clarify the patient's condition and prognosis, to make decisions regarding the focus of treatment, that is not just curative but also palliative, to discontinue or limit therapeutic efforts, not performing resuscitation, providing a more natural death with family involvement for better coping with bereavement; (3) integrated and coherent multidisciplinary teamwork. The work showed some failures in the performance of Palliative Care actions regarding communication with the patient and family, reviewing techniques to approach critical issues. In addition, there is some problem regarding the communication among staff members, both through meetings and record detailing, which would facilitate information sharing during shift changes, and there is still a need for investment in the emotional health of

Palliative Care staff, that was recommended, but was not implemented in any of the studies analyzed. The articles pointed out that Palliative Care actions provided in neonatal intensive care units are poorly structured, which suggests that other studies may be conducted to support the implementation of Palliative Care protocols and guidelines that offer theoretical contributions for reflection-action by managers and health professionals dedicated to supporting family members in this sensitive and unique moment.

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