



Palliative care in neonatology from nurses' perspective

Cuidados paliativos em neonatologia sob a ótica do enfermeiro *Cuidados paliativos en neonatología desde la perspectiva de la enfermera*

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ABSTRACT

Objective: to grasp nurses' perceptions and experiences about palliative care in neonatology. **Method:** qualitative research, with palliative care as its conceptual basis, carried out with nurses working in Neonatal Intensive Care Units of three hospitals located in a municipality in the northern region of Paraná. Data were collected from November 2019 to January 2020, analyzed using the Discourse of the Collective Subject methodological framework. **Results:** twenty nurses participated, most of them with less than 5 years of experience. Three topics reflect nurses' perceptions and experiences: 1) Palliative care: from training to professional experience; 2) Meaning palliative care in neonatology; 3) Eligibility for neonatal palliative care. **Conclusion and implications for practice:** nurses report gaps in their training for assisting newborns in palliative care; however, many presented an understanding of the meaning of palliative care with a focus on quality of life of babies affected by an incurable situation or illness, including the family. These aspects point to the need for training and health education focused on this topic as well as the implementation of palliative care in the neonatology service.

Keywords: Palliative Care; Neonatology; Quality of Life; Newborn; Intensive Care Units, Neonatal.

RESUMO

Objetivo: apreender as percepções e vivências de enfermeiros sobre os cuidados paliativos em neonatologia. **Método:** pesquisa de abordagem qualitativa, tendo como base conceitual os cuidados paliativos, realizada com enfermeiros atuantes em Unidades de Terapia Intensiva Neonatal de três hospitais localizados em um município na região norte do Paraná. Os dados foram coletados no período de novembro de 2019 a janeiro de 2020, analisados por meio do referencial metodológico Discurso do Sujeito Coletivo. **Resultados:** participaram 20 enfermeiros, em sua maioria com tempo de experiência menor que 5 anos. Três temas traduzem as percepções e vivências dos enfermeiros: 1) Cuidados paliativos: da formação à vivência profissional; 2) Significando os cuidados paliativos em neonatologia; 3) Elegibilidade para os cuidados paliativos neonatais. **Conclusão e implicações para a prática:** o enfermeiro refere lacunas em sua formação para a assistência ao recém-nascido em cuidados paliativos, no entanto muitos apresentaram a compreensão do significado de cuidados paliativos com foco na qualidade de vida dos bebês acometidos por uma situação ou doença incurável, incluindo a família. Tais aspectos apontam para a necessidade de formação e educação em saúde voltada para essa temática, bem como a implantação dos cuidados paliativos no serviço de neonatologia.

Palavras-chave: Cuidados Paliativos; Neonatologia; Qualidade de Vida; Recém-Nascido; Unidades de Terapia Intensiva Neonatal.

RESUMEN

Objetivo: comprender las percepciones y experiencias de los enfermeros sobre los cuidados paliativos en neonatología. **Método:** investigación cualitativa, con base conceptual en los cuidados paliativos, realizada con enfermeros que actúan en Unidades de Cuidados Intensivos Neonatales de tres hospitales ubicados en un municipio de la región norte de Paraná. Los datos fueron recolectados desde noviembre de 2019 a enero de 2020, analizados mediante el marco metodológico Discurso del Sujeto Colectivo. **Resultados:** participaron 20 enfermeras, la mayoría con menos de 5 años de experiencia. Tres temas reflejan las percepciones y experiencias de los enfermeros: 1) Cuidados paliativos: de la formación a la experiencia profesional; 2) Significado de los cuidados paliativos en neonatología; 3) Elegibilidad para cuidados paliativos neonatales. **Conclusión e implicaciones para la práctica:** las enfermeras reportan lagunas en su formación para asistir a los recién nacidos en cuidados paliativos, sin embargo, muchas presentaron una comprensión del significado de los cuidados paliativos con un enfoque en la calidad de vida de los bebés afectados por una situación o enfermedad incurable, incluyendo la familia. Estos aspectos apuntan a la necesidad de capacitación y educación en salud enfocada en este tema, así como la implementación de cuidados paliativos en el servicio de neonatología.

Palabras clave: Cuidados Paliativos; Neonatología; Calidad de Vida; Recién Nacido; Unidades de Cuidado Intensivo Neonatal.

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INTRODUCTION

Over time, the concept of palliative care (PC) has changed, and what was considered care for patients without the possibility of cure began to have a perspective and focus that provides quality of life for patients and their families in the face of a disease that threatens continuity of life, supporting suffering prevention and relief.¹⁻³ PC requires rapid identification, assessment and treatment of pain and other problems of a physical, psychosocial and spiritual nature as well as the development and execution of a care plan involving the multidisciplinary team and family.¹⁻⁴

PC in the health area has been gaining new meanings and, therefore, expanding its knowledge. The term palliative, derived from the Latin *pallium*, which means to protect, emerges from the medieval period in which *pallium* names the cloak used by knights to protect themselves from storms along the paths they traveled.⁵

PC, then, means protecting, i.e., enabling strategies that can improve quality of life and reduce the suffering of every eligible patient.³⁻⁴ However, few professionals and family members have knowledge and mastery of this topic, especially when it involves newborns (NBs) and children, as they represent the beginning of life cycle.

It is estimated that, annually, 21 million children need PC.⁶ Approximately 2.5 million of them die each year from serious health-related suffering and around 98% are in low- and middle-income countries.⁷

When looking back at NBs hospitalized in Neonatal Intensive Care Units (NICUs), it appears that many have unfavorable diagnoses that could limit their lives, and, in this context, it is observed that several protocols have been developed with a view to PC; however, its implementation has not occurred due to numerous obstacles, such as difficulty in training the team and acceptance by professionals and family members. Furthermore, the focus of these protocols is end-of-life interventions, which leaves a gap in PC's real objective in neonatology, which is to seek to improve quality of life and comfort from the beginning of impossibility of cure.⁸

In this context, there is a need to deepen and carry out PC in the neonatal and pediatric population with a focus on preventing and alleviating suffering.³ Therefore, the following problematizing question emerged: how do nurses working in NICUs understand palliative care in neonatology? Therefore, this study aimed to understand the perceptions and experiences of nurses regarding palliative care in neonatology.

METHOD

This is a qualitative study that adopted the PC assumptions, defined by the World Health Organization (WHO), as its conceptual basis. These assumptions are aimed at assistance that seeks to prevent and reduce the suffering of patients as well as their families who face complications associated with potentially fatal diseases. To this end, they emphasize the importance of a

teamwork approach, in order to offer support to both the person who is the focus of care and their caregivers, which includes attention to practical and therapeutic needs, support in times of pain and physical suffering, psychological, social and spiritual. PC's basic purpose is to support and assist the person to live as actively as possible until death.¹⁻³

Furthermore, PC aims to prevent and alleviate the suffering of adult and pediatric patients and their families, affected by situations associated with potentially fatal diseases, including physical, psychological, social and spiritual suffering.³

In order to qualify the study writing, the COnsolidated criteria for REporting Qualitative research (COREQ) guidelines were adopted.⁹

The study setting was the NICU of three hospitals located in northern Paraná, identified here as hospitals A, B and C.

Hospital A is accredited by the Brazilian Health System (SUS - *Sistopic Único de Saúde*), characterizing itself as a public institution, considered a Regional Reference Center. Its structure includes medical and surgical, pediatric, maternity, surgical center (SC), emergency room, Adult, Pediatric and Neonatal Intensive Care Unit (ICU) units, and Neonatal Intermediate Care Unit (ICaU). The NICU has ten beds.

Hospital B is private, accredited by the SUS and several health plans, and is classified as a philanthropic institution and a reference in the care of high-risk pregnant women at tertiary level. It has medical and surgical hospitalization units, pediatrics, maternity, Neonatal ICaU, Adult ICU, Neonatal/Pediatric, Coronary Unit, SC and emergency room. The NICU and pediatric ICU have 10 beds, 6 of which are neonatal and 4 are pediatric.

Hospital C is accredited by the SUS, but serves several health plans and is characterized as a philanthropic institution. It has a large structure and only serves patients aged between zero and 12 years. It has an emergency room, pediatric medical and surgical inpatient unit, SC and Pediatric and Neonatal ICU. The NICU has eight beds.

It is noteworthy that only in hospital A is there a movement to implement PC in the neonatology service, however, at the time of data collection, it was incipient.

Nurses working in the NICU of the three hospitals in the study municipality participated in the study. Nurses who had worked in the NICU for at least six months were included. Nurses who, at the time of data collection, were absent due to vacation or sick leave were not included.

During the collection period, 25 nurses met the inclusion criteria, however three nurses refused to participate and two interviews were disregarded due to a recording error. Thus, there were a total of 20 participating nurses.

Data collection was carried out from November 2019 to January 2020 through interviews. It should be noted that these interviews took place individually, before the start of working hours, on a previously scheduled day. The locations for the interviews were chosen by nurses (meeting room, offices and multidisciplinary rooms) with the aim of ensuring privacy.

The information collected was recorded using a digital recorder and later transferred to the computer, and transcriptions were made. A field diary was also used where the researcher could write down his perceptions during the interview. It is worth noting that, after completing the interviews, nurses were invited to listen to their recordings and make changes, if they so desired. The interviews were guided by a script prepared by the researchers, and contained two parts: the first referring to nurse characterization and the second referring to the objective itself. The main guiding questions used in the interview to motivate nurses' speech were: during your training, did you have any contact with PC (courses, events, training)? If yes, talk about what it was like, what you remember about the topic. For you, what is PC? And thinking about your work environment and the characteristics of the babies you care for in your unit, in what situations do you believe PC should occur? Why? To this end, a pilot test was carried out in which three nurses participated, one from each institution field of study and, after validation, there was no need to change the instrument. It should be noted that these nurses were not included in the study sample.

The research invitation occurred in person. The main researcher attended the units in the three periods and made the invitation. Upon acceptance, the best time for collection was scheduled, depending on nurses' availability. The interviews were conducted by the main researcher, who was a nurse with knowledge of PC. The mean duration of the main researcher's meeting with participants was approximately 30 minutes, considering the initial interaction and the interview itself.

For data analysis, the methodological framework adopted was the Discourse of the Collective Subject (DCS), which aims to organize and tabulate qualitative data in a discursive way, with the aim of clarifying what a certain population thinks or lives about a certain topic.¹⁰

In this study, nurses working in three different institutions that served the neonatal population were included. Despite belonging to institutions with different characteristics, they serve the same public, and all experience end-of-life care situations as well as providing assistance to NBs considered eligible for PC. The three proposed methodological figures were used: key expression; central idea (CI); and DCS. A key expression is a methodological figure that shows the essence of a statement, or what a subject said about a certain subject. Furthermore, a CI includes a description of the meaning present in key expression. In DCS, qualitative data are presented through a synthetic speech, written in the first person singular with extracts from statements of similar meaning that are considered most important.^{10,11}

To arrive at the synthesis speech, two speech analysis instruments were used. The key expressions found in each interview were transcribed into the discourse analysis instrument 1. These expressions represented the axes defined for analysis. After this transcription, the CI of each key expression were highlighted. The key expressions from all interviews related to the highlighted CI were organized and transcribed into discourse

analysis instrument 2. This allowed the creation of a DCS for each CI. To build the DCS, key expressions were organized into groups so that they formed a coherent speech. To this end, connectors were used in order to give meaning to the DCS, without altering the structure of the sentence prepared by subjects.^{10,11}

For a better understanding of the analysis carried out and to preserve participant anonymity, their names were replaced by the acronym Nur. followed by the numerical sequence based on the order in which the interviews were carried out and the letter that corresponded to the hospital where they worked (Nur. 1A).

The research was approved by the Research Ethics Committee, under Certificate of Presentation for Ethical Consideration (CAAE - *Certificado de Apresentação para Apreciação Ética*) 14997219.1.0000.5231 and Opinion 3.665.201, in October 2019, in accordance with Resolution 466/2012.¹² All participants signed the Informed Consent Form (ICF).

Regarding the definition of sample saturation, the theoretical saturation criterion was not used, and all nurses who met the inclusion criteria were interviewed. This care was taken, as it is a subject little discussed in neonatal units, with the aim of listening to as many nurses from different institutions as possible on the topic. It is worth noting that it was possible, at the end of the interviews, to answer the research question, and that no new elements were found in participants' information.

RESULTS

A total of 20 nurses aged between 20 and 30 years participated, the majority (14) having worked in the NICU for less than 5 years. Of these, 18 had a graduate degree at the *lato sensu* level and two *stricto sensu* (master's level).

From the speeches analyzed, nine central ideas emerged, which were grouped into three topics: 1) Palliative care: from training to professional experience (CI1 - First contact; CI2 - Deficiency in training; CI3 - Awakening to palliative care); 2) Meaning palliative care in neonatology (CI4 - Promoting comfort and quality of life; CI5 - Reducing unnecessary interventions; CI6 - From palliative to terminality; CI7 - Inserting the family into care); 3) Eligibility for neonatal palliative care (CI8 - Palliative care based on prognosis; CI9 - Palliative care after exhausting therapeutic plan).

Topic 1 - Palliative care: from training to professional experience

The first contact with PC occurred at different times during the training process. For some, it occurred during graduation, however with a focus on adult patients and their families. Others had the opportunity to approach the subject of PC to NBs only in graduate degree.

CI1 - First contact

DCS1: the first contact I had with PC was during my undergraduate course, in a discipline aimed at adults, but it was during my graduate studies that this care for NBs was addressed.

I got closer to the topic where I was included in discussions and participated in neonatology conferences, which at times talked about this subject. I note that my service has emphasized a lot about this practice, with the aim of implementing a PC commission and due to the current need, although it has not provided training to professionals to date (Nur. 1A, Nur. 3A, Nur. 4A, Nur. 5A, Nur. 6C, Nur. 8B, Nur. 11A, Nur. 14B, Nur. 18B, Nur. 19A, Nur. 20A).

In contrast, nurses highlighted a deficiency in technical-scientific training related to PC, specifically in neonatology. We know the specificities of infant care and this also occurs in PC; Therefore, adequate training is necessary for the care plan to be effective for NBs and their family.

CI2 – Deficiency in training

DCS2: I had little contact during undergraduate and graduate studies in one discipline, but it was related to PC in adults. In neonatology and pediatrics, we had some superficial research group and internship discussions (Nur. 6C, Nur. 9A, Nur. 17B).

DCS3: I don't remember a course or event related to PC during my undergraduate studies; I think a few years ago this wasn't even talked about. I participated in conferences where the topic was discussed, but nothing related to NBs (Nur. 10C, Nur. 12A, Nur. 13A, Nur. 15B, Nur. 16C).

However, some nurses reported that movements aimed at PC in their work environment aroused their interest in the topic.

CI3 - Awakening to palliative care

DCS4: currently, here at my service, there has been a lot of talk about PC, countless research is taking place, which has sparked my interest. There was an event for the staff here with a presentation by a professional reporting his experience in this care and some informal guidance. I also participated in some lectures of my own free will, as the service, for now, did not provide training (Nur. 1A – Nur. 5A, Nur. 8B).

Topic 2 - Meaning palliative care in neonatology

Even though the majority of nurses reported a lack of training in PC in neonatology, they understand this care as promoting comfort and quality of life and reducing procedures that may cause pain as well as involving the family in this process.

CI4 – Promoting comfort and quality of life

DCS5: PC is the care we must take to improve quality of life and promote comfort for those who have an incurable disease that could make life difficult or who are in the process of terminal illness. It is to provide pain relief, diet, according to patients' needs, offer conditions for treatable situations, avoid unnecessary interventions and heroic measures that prolong the suffering of those involved, respecting and including the family in this care together with a multidisciplinary team, discussing processes (Nur. 1A, Nur. 2A, Nur. 3A, Nur. 5A, Nur. 6C, Nur. 7C, Nur. 8B, Nur. 10C, Nur. 12A, Nur. 13A, Nur. 15B).

CI5 – Reducing unnecessary interventions

DCS6: I believe that, in PC, we should avoid unnecessary procedures and interventions, such as collecting unlimited tests, heroic attitudes, such as resuscitation, use of vasoactive drugs to maintain cardiac contractility, in order to provide adequate treatment with comfort, whether treating an infection, controlling pain, sedating and if it stops do not resuscitate, including the family in the events (Nur. 2A, Nur. 3A, Nur. 5A, Nur. 12A, Nur. 14B).

CI6 – From palliative to terminality

DCS7: palliative, for me, is offering comfort, dignity and humanization to patients and their family, promoting a better quality of life and tranquility in the progression towards death in their final days, with good hygiene, medicating as needed, without invasive measures and with more time and proximity to your loved ones. I also consider case discussion and care planning among all team members important (Nur. 9A, Nur. 11A, Nur. 16C, Nur. 17B).

CI7 – Inserting the family into care

DCS8: PC is all the care that we try to provide in the most holistic way possible, including the family in direct care within the unit, providing parents with spiritual comfort, respecting their beliefs and updating them on patients' clinical condition. I consider pain relief important and difficult to control in this population and, when terminally ill, communication between professionals needs to be more than present and uniform (Nur. 5A, Nur. 9A, Nur. 18B, Nur. 19A, Nur. 20A).

Topic 3 – Eligibility for neonatal palliative care

The lack of clarity about which NBs are eligible for PC becomes a barrier to implementing the care process. Despite this, in nurses' statements, there are some diseases and situations that they judged to be indicative for the beginning of PC.

CI8 – Palliative care based on prognosis

DCS9: it is not very clear which diseases in the neonatal population are indicative for PC, due to the delay in reaching a prognosis, but I think the difference between babies who deserve this care are those who have an underlying pathology or when the prognosis does not lead to good survival, such as, important malformations and syndromes incompatible with life, such as Edwards, Patau, anencephaly, hydrocephalus, with bilateral renal agenesis, dialysis, pulmonary hyperplasia and hypoplasia, severe heart diseases, imperfect osteosynthesis, and also extreme or moderate premature babies born under 600 grams and with complications during care. Other cases that I think would be indicated would be babies who need major surgery, such as omphalocele, encephalocele and those who have received several cardiopulmonary resuscitations (CPR) and high dose drugs without therapeutic response (Nur. 1A, Nur. 2A, Nur. 3A, Nur. 4A, Nur. 5A, Nur. 9A, Nur. 11A, Nur. 12A, Nur. 13A, Nur. 14B, Nur. 17B, Nur. 19A, Nur. 20A).

However, it is observed in the following speech that, for some nurses, the indication should only occur after exhausting all therapeutic measures.

CI9 – Palliative care after exhausting therapeutic plan

DCS10: should use PC when all therapeutic measures have been carried out, such as antibiotics, drugs and that did not respond adequately to treatment, which is why it becomes more difficult in neonatology. We always want them to improve and go home, with a deficit or not. In this case, I believe it would be recommended for patients with heart disease with postoperative complications, encephalopathy, chronic non-evolutionary encephalopathy, extremely premature babies with no prospect of life or after several attempts at CPR (Nur. 7C, Nur. 8B, Nur. 10C, Nur. 18B).

DISCUSSION

PC generally represents a major challenge for health professionals, especially those working in neonatal units, since nurses participating in this study mentioned little approach to this topic in their training, whether during their undergraduate or graduate studies. PC, especially in neonatology services, is still a new process in Brazil and faces numerous barriers to its insertion.

The inclusion of PC in academic training can provide knowledge on the topic and, therefore, prepare professionals to deal with the process of death and dying. This gap associated with the lack of psychological and emotional support to face situations of tension and conflicts can make such activity even more difficult, as the end-of-life process for an infant is something that shakes professionals.^{13,14}

Due to the difficulties in the PC training process during the academic period, nurses mention that, despite the barriers, they began their experience of this topic in their work environment and, given this experience, they became aware of the subject. Working in the NICU and monitoring the process of NBs' death and family mourning are challenges to be faced by nurses, as many feelings emerge from this care and one of them is due to failure in their role of health promotion and recovery.¹³

The modality of care must be carried out by qualified and trained health professionals, in order to promote the well-being and quality of life of critically ill patients or patients with incurable diseases who are experiencing intense suffering. Patients' autonomy, individuality, dignity and wishes must also be respected.^{3,13-15}

In this study, it was observed that nurses do not feel prepared, as they are young professionals with little time working in the area, and, in general, they report not receiving training for this role.

In contrast, although nurses reported a deficit in their training, they considered PC in neonatology as care that aims to promote comfort and quality of life for NBs with incurable, complicated or terminal diseases. Furthermore, they see the family as an integral part of this process.

Professionals also understand that reducing unnecessary interventions is part of this care and, even if they may be overly accustomed to new devices, which are produced with the aim of saving lives and providing hope to families of terminally ill patients, this is not always an option. We know the need and importance of pain control and symptom relief, and this is one of the principles of PC, in addition to comfort, offering quality of life and reducing suffering.¹⁶

Infants are subject to several potentially painful procedures that can compromise their neuropsychomotor development and clinical recovery, with pain being undertreated, whether intense, moderate or mild.¹⁷

In this regard, the study points out that nurses understand PC as a time when interventions must be reduced with the aim of alleviating suffering. The research results corroborate the literature, indicating that some of those involved face internal conflicts when providing care to patients with no possibility of cure, having doubts as to whether this would be the best conduct, or when they think about their families or themselves and, when putting themselves in the other person's shoes, present a storm of questions.^{13,18}

Some nurses experienced positively the conduct of PC aimed at patients at the end of life, even if, when meaning this care, they have difficulty discerning between patients with an incurable disease and terminally ill patients. This corroborates a study regarding nurses' perception of PC, in which it was observed that, before being trained on the subject, they believed and meant it as a dignified death, but, after being trained, this conception changed to PC as a guarantee of care to promote quality of life.¹⁹

The inclusion of the family in the process of caring for babies eligible for PC was mentioned by nurses, as professionals must turn their attention not exclusively to NBs, but to their family member who faces a moment of countless doubts, uncertainties and conflicts in the face of an unknown context.

Communication is an important therapeutic tool and should be shared with the family to promote comprehensive and humanized care, as well as to establish interpersonal relationships,²⁰ because, through listening and looking carefully,^{20,21} nurses aim to reduce anxiety and fear of the disease and the future that awaits them.²¹

NB care must be proportional to the clinical condition and the real possibility of each individual's response. Therefore, complying with family members' plans, ensuring that NBs do not suffer and offering psychological and spiritual support are considered actions that should guide the care offered at these times.^{19,22}

However, for some nurses, the moment to include NB in PC is not clear, generating numerous doubts and the need for further clarification about the pathology and prognosis. However, other nurses do not share this opinion, as they consider that NBs should only be eligible for PC when all therapeutic resources have been exhausted.

Therefore, there is still a long way to go to define more clearly which NBs need a palliative approach throughout their lives as well as the need for permanent and continuous training and discussions between multidisciplinary teams for more appropriate care that encompasses children and their families throughout the process and evolution of their diagnosis and prognosis.²²

Neonatology does not have functionality assessment scales that allow estimating the prognosis for NBs and, as a result, differences in conduct occur that can interfere with communication between the team and family members. The meaning of PC must be clarified to everyone involved so that they understand that having a child eligible for PC does not necessarily mean that they are in an active process of death.²²

Although nurses reported not having been trained for PC and having doubts about the eligible criteria, it was observed that most participants in this research reported diagnoses that, according to some studies, are considered situations that converge with this philosophy of care.

CONCLUSION AND IMPLICATIONS FOR PRACTICE

It was possible to identify that, despite the difficulties in the continuing education process, at some point, participating nurses were closer to the topic and experienced situations of NBs that fit into PC practice.

Nurses understand the meaning of PC as a time to offer welcome and care to the baby and his family when there is no prospect of a cure and with a focus on quality of life. Furthermore, it was noticed that there are divergences regarding the understanding of PC for NBs with no prospect of a cure and for those who are at the end of life. However, it was observed that some nurses still understand that this care should be offered to the child only after all therapeutic measures have been carried out.

In this regard, it is necessary for health institutions to broaden their perspective on PC and actions to be carried out to raise awareness and train nursing professionals so that they can care for NBs and their families, aiming to improve quality of the care process as well as the need to implement PC in the neonatology service.

This research was limited by the use of informants from only one professional category, which did not allow for comparing the conduct and opinions of the multidisciplinary team that works in neonatology services and, therefore, expanding knowledge on this issue. It is also important that new studies be carried out with the multidisciplinary team, in order to identify whether, in other areas of care, this issue is already a reality or whether it is necessary to invest in health education about PC for all categories of health professionals.

AUTHOR'S CONTRIBUTIONS

Study design. Cíntia Martins Lacerda Dantas. Adriana Valongo Zani.

Data collection. Cíntia Martins Lacerda Dantas. Adriana Valongo Zani.

Data analysis. Cíntia Martins Lacerda Dantas. Adriana Valongo Zani. Juliane Pagliari Araujo. Sonia Silva Marcon. Rosângela Aparecida Pimenta.

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REFERENCES

1. World Health Organization. Integrating palliative care and symptom relief into paediatrics: a WHO guide for health care planners, implementers and managers [Internet]. Geneva: WHO; 2018 [cited 2022 apr 21]. Available from: <https://apps.who.int/iris/bitstream/handle/10665/274561/9789241514453-eng.pdf?sequence=1&isAllowed=y>
2. Sociedade Brasileira de Pediatria. Cuidados paliativos pediátricos: o que são e qual a sua importância? Cuidando da criança em todos os momentos. Vol. 1 [Internet]. Rio de Janeiro: SBP; 2017. Documento Científico [cited 2022 aug 18]. p. 1-9. Available from: https://www.sbp.com.br/fileadmin/user_upload/2017/03/Medicina-da-Dor-Cuidados-Paliativos.pdf
3. Maingué PCPM, Sganzerla A, Guirro UBP, Perini CC. Discussão bioética sobre o paciente em cuidados de fim de vida. Rev Bioet. 2020;28(1):135-46. <http://dx.doi.org/10.1590/1983-80422020281376>.
4. Camilo BHN, Serafim TC, Salim NR, Andreato AMO, Roveri JR, Misko MD. Comunicação de más notícias no contexto dos cuidados paliativos neonatal: experiência de enfermeiros intensivistas. Rev Gaúcha Enferm. 2022;43:e20210040. <http://dx.doi.org/10.1590/1983-1447.2022.20210040>. PMID:35043878.
5. Academia Nacional de Cuidados Paliativos. O que são cuidados paliativos [Internet]. São Paulo: Academia Nacional de Cuidados Paliativos; 2020 [cited 2022 aug 18]. Available from: <https://paliativo.org.br/cuidados-paliativos/o-que-sao/>.
6. Connor SR, Downing J, Marston J. Estimating the global need for palliative care for children: a cross-sectional analysis. J Pain Symptom Manage. 2017;53(2):171-7. <http://dx.doi.org/10.1016/j.jpainsymman.2016.08.020>. PMID:27765706.
7. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X et al. Alleviating the access abyss in palliative care and pain relief: an imperative of universal health coverage: the Lancet Commission report. Lancet. 2017;391(10128):1391-454. [http://dx.doi.org/10.1016/S0140-6736\(17\)32513-8](http://dx.doi.org/10.1016/S0140-6736(17)32513-8). PMID:29032993.
8. Dombrecht L, Chambaere K, Beernaert K, Roets E, Keyser MV, Smet G et al. Components of perinatal palliative care: an integrative review. Children. 2023;10(3):482. <http://dx.doi.org/10.3390/children10030482>. PMID:36980040.

9. Souza VR, Marziale MH, Silva GT, Nascimento PL. Translation and validation into Brazilian Portuguese and assessment of the COREQ checklist. *Acta Paul Enferm.* 2021;34:eAPE02631. <http://dx.doi.org/10.37689/acta-ape/2021AO02631>.
10. Lefèvre F, Levèvre AM. Pesquisa de representação social: um enfoque quali-quantitativo. Brasília: Liber Livro; 2011.
11. Minayo MC. O desafio do conhecimento: pesquisa qualitativa em saúde. 11ª ed. São Paulo: Hucitec/Abrasco; 2014.
12. Novoa PCR. What changes in Research Ethics in Brazil: Resolution no. 466/12 of the National Health Council [editorial]. *Einstein.* 2014;12(1):7-10. <https://doi.org/10.1590/S1679-45082014ED3077>.
13. Camilo BHN, Serafim TC, Salim NR, Andreato AMO, Roveri JR, Misko MD. Comunicação de más notícias no contexto dos cuidados paliativos neonatal: experiência de enfermeiros intensivistas. *Rev Gaúcha Enferm.* 2022;43:e20210040. <http://dx.doi.org/10.1590/1983-1447.2022.20210040>. PMID:35043878.
14. Verri ER, Bitencourt NAS, Oliveira JAS, Santos Jr R, Marques HS, Porto MA, Rodrigues DG. Profissionais de enfermagem: compreensão sobre cuidados paliativos pediátricos. *Rev Enferm UFPE on line.* 2019;13(1):126-36. <http://dx.doi.org/10.5205/1981-8963-v13i1a234924p126-136-2019>.
15. Silva RS, Pereira A, Nóbrega MML, Mussi FC. Construction and validation of nursing diagnoses for people in palliative care. *Rev Latino-Am Enfermagem.* 2017;25:e2914. <https://doi.org/10.1590/1518-8345.1862.2914>.
16. Picollo DP, Fachini M. A atenção do enfermeiro ao paciente em cuidado paliativo. *Rev Ciênc Med.* 2018;27(2):85-92. <http://dx.doi.org/10.24220/2318-0897v27n2a3855>.
17. Costa ACL, Araújo FL, Simão DAS, Bueno M, Marcatto JO, Manzo BF. Análise correlacional entre procedimentos potencialmente dolorosos e estratégias de controle da dor em unidade neonatal. *Texto Contexto Enferm.* 2019;28:e20180299. <http://dx.doi.org/10.1590/1980-265x-tce-2018-0299>.
18. Moraes EN, Conrad D, Mattos EM, Cruz SAC, Machado GC, Abreu MO. Cuidados paliativos: enfrentamento dos enfermeiros de um hospital privado na cidade do Rio de Janeiro. *Rev Pesqui.* 2018;10(2):318-25. <http://dx.doi.org/10.9789/2175-5361.2018.v10i2.318-325>.
19. Silva HA, Viana GKB, Lima AKG, Mourão CML, Lima ALA. Intervenção em cuidados paliativos: conhecimento e percepção dos enfermeiros. *Rev Enferm UFPE on line.* 2018;12(5):1325-30. <http://dx.doi.org/10.5205/1981-8963.2018.22653>.
20. de Andrade CG, Costa ICP, Batista PSS, Alves AMPM, Costa BHS, Nassif MS et al. Cuidados paliativos e comunicação: uma reflexão à luz da teoria do final de vida pacífico. *Cogitare Enferm.* 2022;27:e80917. <http://dx.doi.org/10.5380/ce.v27i0.80917>.
21. Andrade GB, Pedroso VSM, Weykamp JM, Soares LS, Siqueira HCH, Yasin JCM. Cuidados paliativos e a importância da comunicação entre o enfermeiro e paciente, familiar e cuidador. *Rev Fund Care Online.* 2019;11(3):713-7. <http://dx.doi.org/10.9789/2175-5361.2019.v11i3.713-717>.
22. Gibelli MABC. Cuidados paliativos em recém-nascidos: quem são esses pacientes? In: Sociedade Brasileira de Pediatria, Procianny RS, Leone CR, organizadores. PRORN Programa de Atualização em Neonatologia: ciclo 17. Porto Alegre: Artmed Panamericana; 2020. p. 77-101.