



**MORTE EM NEONATOLOGIA: VIVÊNCIAS DOS PROFISSIONAIS DE SAÚDE NA PRESTAÇÃO DE CUIDADOS PALIATIVOS NEONATAIS**

**END OF LIFE IN NEONATOLOGY: EXPERIENCES OF HEALTH PROFESSIONALS IN NEONATAL PALLIATIVE CARE**

**MUERTE EN NEONATOLOGÍA: VIVENCIAS DE LOS PROFESIONALES DE SALUD EN LA PRESTACIÓN DE CUIDADOS PALIATIVOS NEONATALES**

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RECEIVED: 02<sup>th</sup> February, 2019

ACCEPTED: 20<sup>th</sup> March, 2019

## RESUMO

**Introdução:** Recentemente, tem-se constatado que os profissionais que trabalham nas Unidades de Cuidados Intensivos Neonatais mostram um interesse crescente pelas decisões tomadas no final da vida e pela qualidade dos cuidados prestados aos recém-nascidos e suas famílias.

**Objetivos:** Compreender as vivências dos profissionais de saúde relativamente aos cuidados paliativos neonatais.

**Métodos:** Utilizou-se a metodologia de investigação qualitativa, exploratório-descritiva, de cariz fenomenológica.

**Resultados:** Foram aplicados e analisados questionários a 15 profissionais a exercer numa UCIN do centro de Portugal. Os dados obtidos revelam carência de formação e inexistência de protocolos/*guidelines*, bem como necessidade de suporte psicológico a profissionais e família do RN.

**Conclusões:** A formação contínua e específica, o apoio e acompanhamento psicológico dos profissionais e das famílias devem constituir o pilar dos cuidados paliativos neonatais.

**Palavras-chave:** cuidados paliativos; neonatologia; recém-nascido; atitude frente à morte; pessoal de saúde

## ABSTRACT

**Introduction:** It has recently been shown that professionals working in neonatal intensive care units (NICUs) show an increasing interest in decisions made at the end of life and in the quality of care provided to newborns and their families.

**Objectives:** To understand the experiences of health professionals regarding neonatal palliative care.

**Methods:** The research methodology was qualitative, exploratory-descriptive and phenomenological.

**Results:** Questionnaires were applied to 15 professionals working at a NICU in central Portugal and subsequently analysed. The data obtained show lack of training and lack of protocols/*guidelines*, as well as the need for psychological support for professionals and the families of the newborns.

**Conclusion:** Continuous and specific training, support and psychological counselling for professionals and families should be the pillar of neonatal palliative care.

**Keywords:** Palliative care; neonatology; infant, newborn; attitude to death; health personnel

## RESUMEN

**Introducción:** Recientemente, se ha constatado que los profesionales que trabajan en las Unidades de Cuidados Intensivos Neonatales muestran un interés creciente por las decisiones tomadas al final de la vida y por la calidad de los cuidados prestados a los recién nacidos y sus familias.

**Objetivos:** Comprender las vivencias de los profesionales de la salud en relación con los cuidados paliativos neonatales.

**Métodos:** Se utilizó la metodología de investigación cualitativa, exploratoria-descriptiva, de carácter fenomenológico.

**Resultados:** se aplicaron y se analizaron cuestionarios a 15 profesionales para participar en una UCIN en el centro de Portugal. Los datos obtenidos revelan carencia de formación e inexistencia de protocolos / pautas, así como necesidad de soporte psicológico a profesionales y familia del RN.

**Conclusiones:** La formación continua y específica, el apoyo y acompañamiento psicológico de los profesionales y de las familias deben constituir el pilar de los cuidados paliativos neonatales.

**Palabras Clave:** Cuidados paliativos; neonatología; recién nacido; actitud frente a la muerte; personal de salud

## INTRODUCTION

The World Health Organization (1998) describes paediatric palliative care as total active care for the body, mind and spirit of the child as well as involving support for the family. Neonatal palliative care is defined as a holistic and extensive approach to both the child with an incurable disease and his or her family in mourning. When palliative care is not provided to end-of-life newborns and their families, they may not receive the specialized and multidisciplinary care they need and deserve (Catlin, & Carter, 2002). Advances in neonatal medicine have meant that children with serious diseases, who cannot survive, can be assisted with quality at the end of their lives (Torres, Goya, Rubia, Jimenez, Munóz & Rodríguez, 2013).

In recent years, professionals working in Neonatal Intensive Care Units (NICUs) have shown a growing interest in the decisions taken at the end of life and in the quality of care provided to both the newborn (NB) and the family (Torres et al., 2013). Thus,

neonatology health professionals and grieving families often receive no assistance or support in fatigue, frustration or sadness when babies die or are in an end-of-life situation (Peng, Chen, Huang, Liu, Lee, & Sheng, 2013).

The attitude of nursing professionals towards death is proportionately related to their attitude toward end-of-life care (Yang, Liu, & Liao, 2008). This therefore implies that positive attitudes and beliefs regarding palliative care are important, and professionals with these characteristics, even at an early stage, provide quality care (Chen, Huang, Liu, Lee, Wu, Chang, & Peng, 2013). The scarce research regarding the experiences health professionals go through, and how they deal with them, may affect their attitude towards death. Thus, these experiences must be identified in order to maintain job satisfaction and the appropriate provision of neonatal palliative care (Chen et al., 2013).

In short, taking into account the pertinence of these issues, this research study is conducted with the overall aim of understanding the experiences of health professionals in relation to neonatal palliative care. The specific aims of our study are: to identify and understand the emotions of health professionals in neonatal palliative care, as well as the moments in which they arise; to see if neonatology health professionals consider undergoing specific training in the area of neonatal palliative care and if they consider it important; to identify the perceived need for protocols/guidelines for the practice of neonatal palliative care; and to understand the importance of providing psychological support to neonatal palliative care professionals.

## 1. THEORETICAL FRAMEWORK

The implementation of palliative care in neonatology is extremely relevant today. With the advance in technology in NICUs from the 1960s, the viability limit for preterm newborns declined drastically, particularly for those with very low birth weight and very low gestational age, proportionally increasing the probability of survival with serious disability. Similarly, there was a substantial improvement in prenatal diagnosis techniques, resulting in increasingly accurate prognostic instruments, as well as an undeniable progress in therapeutic resources (Soares, Rodrigues, Rocha, Martins, & Guimarães, 2013).

In Portugal, the rate of neonatal mortality has decreased significantly over the last decades, decreasing from 6.9% in 1990 to 3.4% in 2002, which corresponds to a decrease of 50.7% and reaching 2% in 2015 (Pordata, 2017).

Taking technical and scientific developments in recent years and their repercussions on the neonatal mortality rate into account, the question of whether anything technically possible is ethically acceptable has arisen. Thus, ethical dilemmas with clear repercussions in clinical practice have emerged. Among these, a greater sensitivity to adopting therapeutic limitations and palliative care is emphasized when attempts to cure patients become futile and therefore clinically and ethically unjustifiable (Peng et al., 2013).

According to the Association for Children's Palliative Care (2009, p.4, cit. by Ministério da Saúde, 2014),

*"palliative care for children and young people is an active and total approach to their care, from diagnosis to recognition, throughout their entire lives and beyond their death. It [palliative care] covers physical, emotional, social and spiritual elements, focusing on improving the quality of life of the child/youth and support for their family, and includes symptom control, provision of rest periods for caregivers, and assistance during the terminal stage and mourning."*

Palliative care presupposes an acceptance of death as an unavoidable phenomenon, focusing on adequate care and comfort for the NB and support for the family. All phases of the newborn's disease should be taken into account during its progression until the final moment, with the aim of helping the NB to achieve a dignified death, respecting it as a person (Torres et al., 2013).

The decision to withdraw or discontinue intensive neonatal care can be made to alleviate suffering. The decision not to reanimate (DNR) is defined in a narrow sense as the decision to renounce cardiopulmonary resuscitation and was formally introduced as an option for end-of-life care (Huang, Chen, Liu, Lee, Peng, Wang, & Chang, 2013).

Health professionals in neonatology have an ethical obligation to administer the treatments that are indicated, as well as not to initiate or suspend treatments considered contraindicated. Continuing resuscitation measures in end-of-life situations presumes violating the ethical principle of *"non-maleficence"* that obliges not to cause harm or injury to the newborn (Peng et al., 2013).

Decision-making should be shared between the care team and parents through a process of deliberation and a choice of possible courses of action, which will best serve the interests of the child. The strategy of waiting for *"absolute certainty"* involves the risk of therapeutic obstinacy, which may cause harm to the newborn, the family, and society in general. It is the parents, as representatives of the child, who have a moral and legal responsibility to give their consent or deny it. In this way, their decisions are definitive unless they conflict with the opinions of the responsible professionals. The participation of parents in decision-making is always a difficult and stressful situation, so decisions should be taken in agreement with professionals (Torres et al., 2013).

Health professionals who experience the pain and suffering of children and their families can also experience their own pain and suffering. These negative feelings can lead to a reluctance to care for newborns at the end of life, as well as lead to an increase in burnout rates. Thus, these feelings should be identified in order to maintain job satisfaction and acceptable delivery of neonatal palliative care (Chen et al., 2013).

## 2. METHODS

Considering the concerns that led us to the development of this study, we opted for a qualitative, exploratory-descriptive, phenomenological study. We based our methodological approach in Fortin, Côte, & Filion (2009), stating that the aim of the qualitative research method is to understand the phenomenon under study broadly. This was also stated by Streubert and Carpenter (2002, p.20), in affirming, "the purpose of phenomenology is to explore the experiences lived by individuals and provides researchers with the framework to discover what experience is like." Thus, we focus on the experiences of health professionals in relation to neonatal palliative care.

### 2.1 Sample

The data were collected in the NICU of a hospital unit in central Portugal and then analysed. The participants were selected through non-probabilistic, intentional sampling, in order to get answers to more specific and differentiated questions. For this, we had to create inclusion criteria, that is, the participants had to be health professionals practising in the NICU mentioned above. The study sample consisted of the health professionals who voluntarily participated and consisted of six paediatricians and nine nurses, for a total of 15 participants (N=15).

### 2.2 Data collection instruments

The instrument used for data collection was the questionnaire, consisting of open and closed questions. Two experts in the area validated the instrument through critical analysis, verifying the pertinence of each question in relation to the objectives of the study. After making the suggested changes, a pre-test was applied to two health professionals of the neonatology department in a hospital not involved in this study, in order to certify the clarity and impartiality of the questionnaire, as well as its adequacy in obtaining information.

To support the understanding and meaning of the data we use the technique of content analysis, based on Amado (2000), Bardin (2009) and some aspects referred to by Streubert and Carpenter (2002).

A random code (N1 to N15) was assigned to each questionnaire. Then, the body of each questionnaire was read carefully, followed by a rereading in order to discover the meanings and to formulate the dimensions, categories and subcategories that emerged. Each questionnaire was analysed individually, since each participant has a valid and sustained experience and opinion. After this step, an attempt was made to apprehend the essential relations, and a representative drawing of the phenomenon was elaborated, which was used as a driver to analyse the data.

### 2.3 Procedures

After receiving a favourable opinion from the hospital's board of directors, the hospital's ethics committee was consulted. Then, with the objectives explained to them and guaranteeing anonymity and confidentiality of the data, all of the participants signed the informed consent form to participate in the study. This ensures compliance with the ethical and legal considerations necessary for the research process.

## 3. RESULTS

After analysing the questionnaires for the sociodemographic characteristics, we found that 100% of the sample was female. As for educational level, 60% of the participants had a degree in nursing, 33.3% of whom had a speciality, 40% had studied medicine specializing in paediatrics. The mean age is 37.27 years, with a standard deviation of 7.79 and had 13.4 years of professional experience. It should be noted that 60% of the respondents have children.

Regarding specific training in palliative care, 86.7% reported not having it. Only 33.3% of the sample provided neonatal palliative care and 73.3% reported they had previously provided end-of-life care. Nearly all respondents, 93.3%, do not equate neonatal palliative care with end-of-life care. The same sample, 93.3% said that there are no protocols/guidelines in the service, even though 86.7% consider them important. There was unanimous agreement among participants on the importance of moments of reflection and being provided psychological support.

Thus, the data obtained are based on the experiences of health professionals marking their work in the provision of palliative care, as well as their opinion about the need for protocols or guidelines for their practice and support. From the data analysis of the open answers, six dimensions emerged: palliative neonatal care, end-of-life care, palliative and end-of-life care, importance of protocols/guidelines, importance of moments of reflection, and importance of psychological support, with respective categories and subcategories, as shown in table 1.

**Table 1:** Dimensions, categories and subcategories of the experience of health professionals in providing neonatal palliative care

<i>Dimension</i>	<i>Categories</i>	<i>Subcategories</i>
<i>Providing neonatal palliative care</i>	Satisfaction in providing care	Tranquillity Gift of prolonging life Doing one's duty Respect for the patient and the family
	Dissatisfaction in providing care	Impotence Anguish Emotional exhaustion Confusing feelings and thoughts
	No experience in providing care	
<i>Providing end-of-life care</i>	Emotionally difficult experience	
	Emotional relief	Peace
<i>Equivalency of palliative and end-of-life care</i>	No experience in providing care	
	Palliative care	Quality of life, comfort and well-being Pain management Managing care
<i>Importance of the existence of protocols/guidelines</i> <i>Importance of moments of reflection</i>	End-of-life care	Emotionally difficult experience Pain management Supporting the family Therapeutic obstinacy
	Standardization of team performance	Clarifying questions Ensuring quality of care
	Group sharing	Sharing of emotions, ideas, experiences Personal and professional enrichment
<i>Importance of psychological support</i>	Personal and professional development	Improving future situations Not feeling guilty Improving care
	Standardization of procedures	
	Availability	
	Emotional and social support	Cause of burnout Learning to deal with the patient

#### 4. DISCUSSION

From the data analysis, we found they are in line with the studies mentioned above (Chen et al., 2013; Soares et al., 2013 & Mendes et al., 2013) which reinforce the fact that health professionals do not have specific training in the area of neonatal palliative care. They also attest to the lack of protocols/guidelines to guide and support care, as well as the absence of formal moments of reflection and psychological support to strengthen coping mechanisms in dealing with neonatal palliative care.

We acknowledge that this study reports on a single unit, so we cannot generalize these results to other neonatal units. However, we can infer that the results obtained are representative of this unit.

Given the wealth of the respondents' replies, it was not easy to sum up all of the information collected and organize it into dimensions, categories and subcategories.

##### Dimensional analysis:

##### Providing neonatal palliative care

The dimension of neonatal palliative care integrates care from diagnosis to acknowledging the situation, throughout life and beyond death. In this dimension, "satisfaction in providing care," "dissatisfaction in providing care," and "no experience in providing care" appear as categories.

According to Battikha, Carvalho, & Kopelman, (2014) and Chen et al. (2013), health professionals place themselves in the parents' shoes regarding their own experience of the death of a loved one. They recognize their own fragility lack of control over illness and death, as N14 says, professionals show "a great respect for the sick NB and the family" and "the whole team is moved" (N10). In addition, for these authors, feelings of anguish, impotence, guilt, suffering and loss are also described when confronted with the limits of modern medicine, of its action and of its inability to achieve the ideal of healing, as described by N6, "feelings of impotence, distress," and N10, "a situation of some emotional exhaustion." Moreover, Battikha et al. (2014) reports that it is the

death of the other, but evokes the finitude in all, as well as other limits, impossibilities and losses. As N3 indicates, “. . . confrontation with the finitude of life . . . the acceptance that the human being does not control everything. Death is not our domain.”

### End-of-life care

In the dimension of end-of-life care, which involves maintaining the life of the newborn at all costs, focusing on invasive and technological care. This dimension includes the following categories: “emotionally difficult experience,” “emotional relief,” and “no experience in providing care.”

Chen et al. (2013) reports that caring for newborns at the end of life is a traumatic experience and Torres et al. (2013) states that doctors and nurses mention palliative care as the most stressful activity of their care practice. These statements are reflected in N5, “*They are always very emotional moments that affect the whole team.*”

End-of-life care presupposes an emotional relief for the professional as it presents a sense of peace and an end to the suffering of the neonate. As N14 says, “*I felt a great peace because of the end of the suffering.*”

### Equivalency of palliative and end-of-life care

This dimension involves a comparison between palliative and end-of-life care and is divided into the categories “palliative care” and “end-of-life care.”

Peng et al. (2013) reported that, with the reduction in the neonatal mortality rate, there are ethical dilemmas with clear repercussions in clinical practice, highlighting a greater sensitivity towards adopting therapeutic limitations and palliative care. With this research involving Portuguese NICU professionals, we found that they mention the same experiences and duality of thought. In particular N8 mentions the “*practice of therapeutic obstinacy*” and N3, “*unnecessary invasive care,*” and often because “*fear . . . invests heavily in the NB*” (N7), thereby practicing end-of-life care, not valuing the newborn’s quality of life. This has the additional issue of delaying the moment of suspending invasive measures by the entire multidisciplinary team, removing the true essence of palliative care.

Soares et al. (2013) mentions that in palliative care there is a greater concern with pain relief at a time when a cure is not expected, which is in line with what N7 and N3 described respectively, “*comfort care (reducing pain)*” and “. . . *promoting comfort, well-being and the absence of pain.*”

### Importance of the existence of protocols/guidelines

This dimension focuses on the importance of the existence of protocols/guidelines that guide and support the provision of neonatal palliative care. “Standardization of team performance” is the only category in this dimension.

Chen et al. (2013) and Soares et al. (2013) have shown that the absence of protocols and guidelines supporting palliative care and the lack of counselling services hamper the implementation of a palliative care model. The existence of rules of guidance accepted by health professionals constitutes a valuable aid to health professionals in the early relief of the suffering of the newborn and his/her family, during a severe and end-of-life neonatal illness (Mendes, J., Silva, L. J., 2013). This was found in comments by N2, N3, N4, N5, N6, N7, N11 and N14 “*So that there is a common thread unifying and guaranteeing quality of care.*”

### Importance of moments of reflection

This refers to formal moments of expression of feelings, active listening to conversations detailing experiences and sharing of ideas and experiences, facilitating the overcoming of difficulties experienced by the professionals, as a team. The categories in this dimension are “group sharing,” “personal and professional development,” and “standardization of procedures.”

Mendes et al. (2013) states that it may often be important to hold meetings after neonatal death for group reflection, constructive assessment of the therapeutic and palliative attitudes adopted and expressing feelings. Most respondents also say, “*Any exchange of experiences and reflection on them is a contribution to the improvement of the care and balance of the team.*” (N13) and “[*They*] *enable group reflection as well as a sharing of ideas and feelings experienced.*” (N6).

Battikha et al. (2014) states that professionals recognize the need to talk about this anguish, which is often borne in silence. As N1 reports, “*At the time I felt the need to share with someone, but I did not have anyone.*”

### Importance of psychological support

Psychological support is critical to prevent burnout and emotional exhaustion. The categories in this dimension are “availability” and “emotional and social support.”

The impending death of a child can generate strong emotions in health professionals, such as defeat, impotence and sadness, which, may require psychological follow-up as stated by N2. “*Given the negative load inherent to this situation, psychological support, as well as group reflection, would facilitate overcoming and going through this phase.*” N6 says, “*It is important for health professionals to be supported in managing feelings/emotions/frustrations . . .*” And N8 reported “. . . *I, myself, have felt the need to talk to someone.*” Peng et al. (2013) mentions in their study that neonatal health professionals and grieving families are often

not assisted in coping with fatigue, frustration or sadness when babies die. With this analysis of the data obtained, we corroborate this situation, since 100% of the respondents answered that they had no psychological assistance, but stress that they consider its existence to be fundamental. *"There are no formal moments; there are informal moments, very generally associated with case gone through at the time,"* says N15. N13 further reinforces that these moments *"are during shift changes or service meetings."* Given the reality that professionals are members of a multidisciplinary team that dedicates more time to the care of the newborn at the end of life, suffering and death are a great emotional burden on them. In our opinion, if this is not valued and properly accompanied it could lead to burnout. In the context of neonatal palliative care, professionals recognize this framework as an important barrier to the provision of quality care (Torres et al., 2013). This was reflected by N14, who stated, *"Caring for the threshold and/or limit of life can cause burnout for dedicated professionals."*

After comparing the results of our questionnaire with the theoretical groundwork, we found that health professionals who provide care in neonatology play an essential role in the defence, promotion and delivery of care to terminally ill newborns and emotional support to their families. It is also noted that the majority of the respondents said they not to provide palliative care due to lack of training. In addition, of the total sample, only one respondent has received training in the area of paediatric palliative care and 100% have had situations of newborns requiring the need for palliative care. The training of professionals is essential to acquire the skills that will make the delivery of quality care possible (Ministério da Saúde, 2014).

In terms of state of the art in Portugal, we found a Consensus on Neonatal Palliative Care and End of Life, from the Portuguese Society of Paediatrics, Neonatology Section, a neonatal palliative care protocol. It states, *"[Palliative care] treats general considerations that may be accepted by neonatologists in general, but we believe that each unit should adapt palliative care to the individualized needs of the newborn and its family"* (Mendes et al., 2013, p.1).

Providing neonatal palliative care requires the development of human and relational skills, in which vocation and individual motivation associated with experience are crucial, but pre- and post-graduate training is indispensable. It is important that decisions involving neonatal palliative care and neonatal death are supported by the entire professional team in order to reach a consensus and so that there are moments after neonatal death for group reflection, constructive evaluation of the therapeutic and palliative attitudes adopted, as well as expressing feelings (Mendes et al., 2013).

*"In spite of the reduced numbers and the trend towards a decline in the mortality rate, considering Perinatal Palliative Care (PPC) in Portugal should be a priority since this age group represents 29% of paediatric deaths with palliative needs"* (Ministério da Saúde, 2014, p. 43).

According to the current reality, many newborns who survive due to the large investment of specialized care need palliative care after this investment. However, in an initial phase the interdisciplinary teams have difficulty assuming that this is a priority. We conclude that a problem of quaternary prevention is continually faced in this context. It must be recognized, valued and dealt with by the professionals involved.

## CONCLUSIONS

Aware of the importance of understanding how health professionals experience palliative and end-of-life care in neonatology, we conducted this study, in order to help us understand the emotional diversity and the moments that are encountered, identifying the difficulties experienced by the health professionals of the NICU under study in relation to care delivery. In addition, the objectives of this study are to understand the existence and importance of specific training in palliative care, as well as the perceived need for service protocols and the possibility of requesting psychological support from professionals.

Taking into account the objectives of the study, we can say that palliative and end-of-life care provokes ambivalent emotions, with negative and impotent emotions predominating, in relation to the need for specific training, protocols/guidelines and psychological support for the professionals involved.

With this study, we have concluded that health professionals consider it important to have moments of sharing and reflecting on the emotions experienced and that, contradictorily, only a minority of them has this opportunity and practice. We consider it, therefore, as a practical implication of the conclusion of the study, that procedures for reflection of emotional experiences be made compulsory, as a form of inter-help, of professional growth to deal with new situations and as a form of identification of excessive interventionism in health, striving for quaternary prevention for the newborns and their families.

Faced with this issue, new studies should be conducted towards discovering other realities and contexts in the country's NICU in order to compare results. Knowing the perception of the experiences of the parents in this context is also an area of research that seems pertinent to us and that would contribute to raise health professionals' awareness on this topic.

We believe that the practice of neonatal palliative care should focus on differentiation and interdisciplinarity, based on continuous, adequate and rigorous training of professionals, as well as regular procedural emotional reflexive practices and individualized psychological support and follow-up when necessary, so that they can provide quality of care for newborns and their families.

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