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EDITORIAL

Death, dying and palliative care in the NICU*

A.A. Eduard Verhagen

University Medical Center Groningen, Department of Pediatrics, University of Groningen, Groningen, the Netherlands

Caring for children with life-threatening or terminal conditions is among the most challenging tasks in pediatrics. This challenge requires healthcare professionals to combine knowledge, skills, and values into an effective effort to promote the patient's quality of life and support the patient's family. Pediatric Palliative Care (PPC) is comprehensive care for infants and children who may not or will not "get better." Although several definitions are proposed in the literature, the following description seems particularly useful because it's both short and accurate: PPC is the art and science of patient and family-centered care, aimed at evaluating and minimizing suffering in all domains (physical, psychosocial, and spiritual), promote shared decision–making and coordinate the care of all children with life-threatening conditions as well as their families.

At the start of PPC developments in the late 1970s, palliative care was synonymous with terminal care. Nowadays, an approach with several distinct stages of care is preferred, based on data and clinical experience.[1] Palliative care starts ideally at the time of diagnosis with blended care that includes disease-oriented treatments together with palliative care. It also includes the stage of end-of-life care, and it extends all through the disease trajectory into bereavement support. Early intervention, preferably by the palliative care team, will facilitate better "total" care from the outset.[2]

Neonatologists are generally very familiar with managing the complexity of newborns' short lives in the context of the relatively high mortality rates associated with prematurity and birth defects. This is why it is essential for healthcare providers working in neonatal intensive care units (NICUs) to prepare to care for infants with life-limiting conditions and to be able to provide family-centered palliative care for both the infant and the family. More infants and families than one might think can benefit from the inclusion of palliative care interventions in routine NICU care.[3,4] However, the ability or willingness of neonatologists to integrate NICU practice with new knowledge and skills coming from interdisciplinary palliative care has varied widely.

In this volume of the Jornal de Pediatria, Marillo Palomo et al.[5] from the Sant Joan de Déu Barcelona Children's Hospital in Spain, report on their experience with the introduction of a neonatal palliative care protocol in their level III NICU. In a retrospective observational study, they compared the main causes of death and modes of death in two different time periods in a single center: from 2009 to 2015, and from 2016 to 2019. The authors aimed to describe causes and modes of death in their unit but also to assess whether the implementation of the protocol had improved end-of-life care. The development of the protocol and training of the NICU staff took place between 2012 and 2015. The protocol contained criteria for recommending transition of intensive care to comfort care, support throughout the care process (monitoring, sedation and analgesia, creation of memory and care for family), and elements of bereavement care for the family after death. Data were derived from the medical files of 344 neonatal deaths.

The authors report that overall, the main causes of death were congenital malformations (45,9%), prematurity related death (25%) and hypoxic-ischaemic encephalopathy (16,2%).

Roughly 75% of deaths occurred after transition or redirection from intensive care to palliative care was made. This transition of care almost always included withdrawal of life sustaining treatments (71,5%) or withholding of additional treatments and/or resuscitation (DNR). The main reason for transition to palliative care was the predicted poor neurocognitive outcome in slightly less than 50% of deaths. Causes and modes of death were largely similar in both time periods.

The intervention of implementing a neonatal palliative care protocol and training of the NICU staff appeared to have a positive effect on end-of-life care. The authors

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[*] See paper by Morillo Palomo et al. in pages 143–8.

E-mail: a.a.e.verhagen@umcg.nl

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report an increase in end-of-life support for the patient and parents after the implementation of the protocol. Parental presence and death in a private room (as opposed to death in the NICU) occurred significantly more often and more photos were made. These are relevant differences because memory-making is an important practice to support and guide family bereavement. It can facilitate a continuing bond with their child.[6]

The study of Marillo Palomo et al.[5] is not without limitations. It is unfortunate, for example, that they did not use uniform definitions of interventions and physiological conditions of the newborns and more details about end-of-life care and the manner in which the newborns in the NICU actually died. Within nations and across national borders, comparisons are increasingly made of mortality rates among hospitals and health care systems, along with comparisons of processes of care provided to infants. Classification schemes are developed to account for all modes of infant deaths, prenatally and postnatally, in order to study differences in processes and quality of care in different institutions and/or countries.[7,8] Uniform classification of deaths is feasible and needed when comparing outcomes between NICUs. It offers an important step towards transparency about the norms and values of stakeholders in decision-making about withholding and/or withdrawing life-sustaining treatments and true comparison of NICU outcomes.

This issue, however, should not distract us from the fact that the analysis and observations made by Marillo Palomo et al.[5] are important and relevant. They show that the course of NICU care for severely ill newborns can be modified if the prognosis becomes really poor. The main intervention they describe is the creation and implementation of a neonatal palliative care protocol, supported by NICU staff training. This combination worked out well in supporting the transition to palliative care for a substantial number of severely ill patients with a poor prognosis and their families. If the authors keep in mind that the study was conducted only a short time after the intervention had started, the results of increased end-of-life support are even more significant and hopeful. These outcomes may open the door to future palliative care interventions in this unit and/or in others. For example: the implementation of perinatal palliative care protocol to combine care, skills, training, and research for pre- and postnatal care. I am sure that future patients, parents, and healthcare providers would profit from that.

Conflicts of interest

The authors declare no conflicts of interest.

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