



## SPECIAL ARTICLE

## Bioethics in end-of-life decisions in neonatology: Unresolved issues<sup>☆</sup>

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Received 31 January 2017; accepted 16 March 2017

**KEYWORDS**

End of life care;  
Decision making;  
Palliative care;  
Donation;  
Moral distress;  
Ethical decisions;  
Neonate

**Abstract** This document is the result of previous work carried out by different expert groups and submitted to multidisciplinary debate at a conference about controversial, deficient, or new aspects in the field of neonatal palliative care, such as: 1) the deliberative decision-making process, 2) hospital and domiciliary palliative care, 3) donation after controlled cardiac death, and 4) moral stress in professionals.

The most relevant conclusions were: the need to instruct professionals in bioethics and in the deliberative method to facilitate thorough and reasonable decision-making; the lack of development in the field of perinatal palliative care and domiciliary palliative care in hospitals

<sup>☆</sup> Please cite this article as: Arnaez J, Tejedor JC, Caserío S, Montes MT, Moral MT, González de Dios J, et al. La bioética en el final de la vida en neonatología: cuestiones no resueltas. An Pediatr (Barc). 2017. <https://doi.org/10.1016/j.anpedi.2017.03.014>

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<sup>◇</sup> Appendix A lists the members of the Working Group on Bioethical Challenges in Neonatology.

**PALABRAS CLAVE**

Cuidados al final de la vida;  
 Deliberación;  
 Cuidado paliativo;  
 Donación;  
 Estrés emocional;  
 Decisiones éticas;  
 Neonato

that attend newborns; the need to provide neonatal units with resources that help train professionals in communication skills and in the management of moral distress, as well as delineate operational procedure and guidelines for neonatal organ donation.

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**La bioética en el final de la vida en neonatología: cuestiones no resueltas**

**Resumen** El presente documento es fruto del trabajo previo realizado por diferentes grupos de expertos y presentado a debate multidisciplinar en unas jornadas sobre aspectos controvertidos, deficientes o nuevos en el cuidado paliativo neonatal, como son: 1) el procedimiento deliberativo en la toma de decisiones; 2) el cuidado paliativo hospitalario y domiciliario; 3) la donación en asistolia controlada, y 4) el estrés moral en los profesionales.

Las conclusiones más relevantes fueron la necesidad de que los profesionales adquieran formación en bioética y se ejerciten en la práctica de la metodología deliberativa para facilitar la toma de decisiones prudentes y razonables; la falta de desarrollo en los hospitales que atienden recién nacidos, del cuidado paliativo perinatal y del cuidado paliativo domiciliario neonatal; la necesidad de facilitar a las Unidades Neonatales recursos que ayuden a capacitar a los profesionales en técnicas de comunicación y de gestión del estrés emocional, así como delinear procesos operativos y protocolos para la donación de órganos.

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**Introduction**

There are instances in which newborns present with problems that threaten their independent life in the first days or weeks of life. On such occasions, health professionals experience concerns as how to act in the best interest of the newborn and the family, continuing life-sustaining treatment or transitioning to palliative care (PC). Thus begins the challenging process of decision making, which involves the participation of the parents as well as every professional who provides care to the child, and requires the consideration of cultural, social and religious factors, among others.<sup>1,2</sup>

In 2013, the Working Group on Ethics of the Sociedad Española de Neonatología (Spanish Society of Neonatology) published an article with recommendations for end-of-life care (EoLC).<sup>3</sup> However, there are still challenges in neonatal units regarding the availability of protocols and guidelines on how to facilitate the delivery of the best possible integral care to patients eligible for PC and their families. On the other hand, some novel and specific aspects associated with neonatal PC, such as home-based PC, organ donation and emotional support for health care professionals, have received little attention and are not known by many neonatology professionals.

In November 2015, a series of scientific meetings of national scope were held and attended by professionals in neonatology, psychology and bioethics to debate the challenges and emerging issues in the practical delivery of neonatal PC. Four workgroups were established with the purpose of developing recommendations based on the scientific literature, ethical principles and personal experience, and this document presents the conclusions that they

reached in relation to: 1) the deliberative process in decision making; 2) hospital-based PC and home-based PC; 3) controlled donation after cardiac death and 4) moral distress in health care professionals.

**Methods**

In the months that preceded the meetings, the coordinator (JA) met regularly with the head of each workgroup (JCT, SC, MM, MTM). Each group summarised the current experience in their field and the evidence found in databases such as PubMed, EMBASE and the Cochrane library. The day of the scientific meetings, brief presentations were made on each topic, specifying the most controversial points, and allowing time for the reflections of the experts in attendance.

In the elaboration of this article, we have used the summary made by each workgroup, the information obtained during the debates and the recordings of the meetings. We have summarised the information in a brief text, presenting the framework of each subject and highlighting the most important contents. We have produced figures and tables to summarise and supplement aspects subject to the most debate or consideration.

**Deliberation as a process for decision making in neonatal care**

Health professionals devoted to the care of ill newborns often face complex decisions with a high clinical and ethical uncertainty. One such scenario is that of patients with a poor prognosis eligible for treatment with aggressive and invasive procedures, but whose potential benefits are questionable

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