


PALLIATIVE CARE IN THE NICU

October 16th, 2025
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Neonatology/Palliative Care

FANNP's National Neonatal Nurse Practitioner Symposium: Clinical Update and Review, 2025 ©


1

No disclosures or conflicts of interest



2

Poll

- How many have received Palliative care training?
- How many are interested in Palliative care in the NICU?
- How many have specific NICU palliative care where they train/work?
- How many think that Palliative care in the NICU is important?

3

Objectives

- Define Palliative Care
- Historical Perspective
- Identify challenges in the NICU population

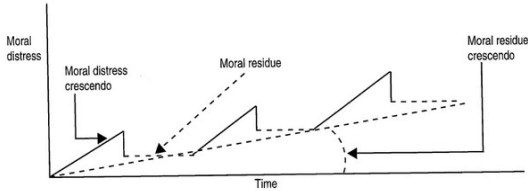
4

My Journey

- Medical Student
- Resident
- NICU Fellow
- Pediatric Palliative Fellow
- NICU/Palliative Attending
- NICU Attending

5

Moral Distress



6



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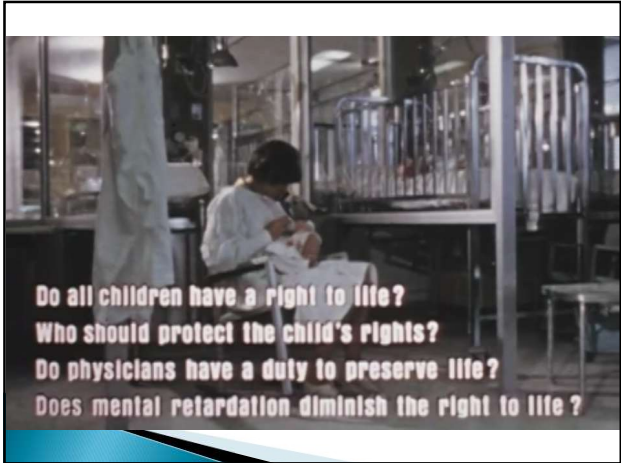
MORAL AND ETHICAL DILEMMAS IN THE SPECIAL-CARE NURSERY
RAYMOND S. DUFF, M.D., AND A.G.M. CAMPBELL, M.B., F.R.C.P. (EDIN.)

Abstract Of 299 consecutive deaths occurring in a special-care nursery, 43 (14 per cent) were related to withholding treatment. In this group were 15 with multiple anomalies, eight with trisomy, eight with cardiopulmonary disease, seven with meningomyelocele, three with other central-nervous-system disorders, and two with short-bowel syndrome. After careful consideration of each of these 43 infants, parents and physicians in a group decision concluded that prognosis for meaningful life was extremely poor or hopeless, and therefore rejected further treatment. The awesome finality of these decisions, combined with a potential for error in prognosis, made the choice agonizing for families and health professionals. Nevertheless, the issue has to be faced, for not to decide is an arbitrary and potentially devastating decision of default. (N Engl J Med 289:890-894, 1973)

"Recently, both lay and professional persons have expressed increasing concern about the **quality of life** for these severely impaired survivors and their families"

"In our opinion, if families regardless of background are heard sympathetically and at length and are given information and answers to their questions in words they understand, the problems of their children as well as the expected benefits and limits of any proposed care can be understood clearly in practically all instances"

8

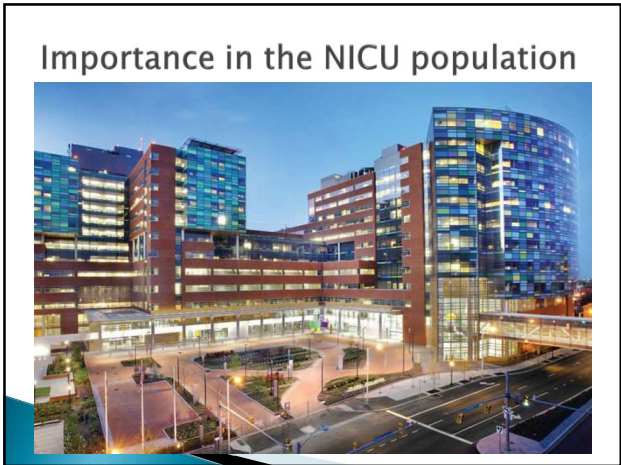


9

"The Hopkins Mongol Case": The Dawn of the Bioethics Movement
Norman Fost, MD, MPH

The image shows a human karyotype with chromosomes arranged in pairs and numbered 1 through 22, plus X and Y. To the right is a detailed diagram of Chromosome 5, showing the p and q arms and the 5p- deletion site.

10



11

The American College of Obstetricians and Gynecologists
WOMEN'S HEALTH CARE PHYSICIANS

ACOG COMMITTEE OPINION
Number 786

Committee on Obstetric Practice
Committee on Ethics

The American Academy of Pediatrics and the Society for Maternal-Fetal Medicine endorse this document. This Committee Opinion was developed by the Committee on Obstetric Practice with the assistance of committee member Russell S. Miller, MD and the American Academy of Pediatrics' liaison member James J. Cummings, MD; and the Committee on Ethics with the assistance of the American Academy of Pediatrics' liaison member Robert Macaulay, MD and the Society for Maternal-Fetal Medicine's liaison member Steven J. Ralston, MD, MPH.

Perinatal Palliative Care

12

Acknowledging Moral Distress

- ▶ Perinatal palliative care team should prepare families for the possibility that there may be **differences of opinion between family members** before and after the delivery of the infant
- ▶ That there may be differences between **parents and the neonatal care providers** about appropriate postnatal therapies

13



14



15

Who Is the Next “Baby Doe?” From Trisomy 21 to Trisomy 13 and 18 and Beyond

Jennifer C. Kett, MD, MA

Trisomy 13 and 18—Treatment Decisions in a Stable Gray Zone

John D. Lantos, MD

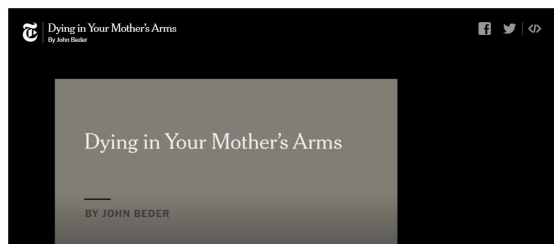
Thirty years ago, pediatric residents were taught that trisomy 13 and 18 were lethal congenital anomalies. Parents were told that these conditions were incompatible with life. There was a tacit consensus that life-sustaining treatment was not medically indicated.¹ Clinical experience usually was consistent with this self-fulfilling prophecy.

Occasionally, though, some infants with these conditions did survive. The children were invariably institutionalized and described as severely impaired.² These case reports were considered as the rare exceptions that proved the rule. In the age of social media, however, everything changed. Parents share stories and videos, showing their happy 4- and 5-year-old children with these conditions. Survival, it turns out, is not as rare as once thought. Children who were not institu-

16

Dying in Your Mother's Arms

A palliative care doctor on finding a “good death” for children in the worst situations.



17



18

References

- ▶ Duff, R.S. Campbell A.G. Moral and ethical dilemmas in the special-care nursery. *N Engl J Med.* 1973 Oct 25;289(17):890-4.
- ▶ Perinatal Palliative Care: ACOG COMMITTEE OPINION, Number 786. *Obstet Gynecol.* 2019 Sep;134(3):e84-e89.
- ▶ Frost N. "The Hopkins Mongol Case": The Dawn of the Bioethics Movement. *Pediatrics* August 2020, 146
- ▶ Nofziger, D. (2020, June 17), *Staff perspective: Moral distress, residue, and the crescendo effect - Understanding the potential impact of the extended COVID-19 crisis*. Center for Deployment Psychology. Retrieved September 1, 2025, from <https://deploymentpsych.org/blog/staff-perspective-moral-distress-residue-and-crescendo-effect-understanding-potential-impact>
- ▶ Kett, J. C. (2020). Who is the next "Baby Doe?" From Trisomy 21 to Trisomy 13 and 18 and beyond. *Pediatrics*, 146(Suppl 1), S9-S12. <https://doi.org/10.1542/peds.2020-0818D>
- ▶ Lantos, J. D. (2016). Trisomy 13 and 18—Treatment decisions in a stable gray zone. *JAMA*, 316(4), 396-398. <https://doi.org/10.1001/jama.2016.9470>