



An update:
**Neonatal
Palliative Care**



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Learning objectives:

- Defining and refining: what is neonatal palliative care – *where have we been, and where are we going?*
- Understand the philosophy of facilitating a 'good death' for neonates with life limiting conditions and the support of families and care givers – *can death ever be good?*



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Once upon a time ...



There wasn't *one*
cardinal event for
me: there were
many ...



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I think we've come a long way?

- "It means not feeding them!"
- "Basically, the baby should be left alone ..."
- "It's not something we really think about with babies - I do know that nobody wants to look after those babies - I think that our more experienced staff should be allocated to those babies who at least have a chance of survival."



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2006: A starting point ...

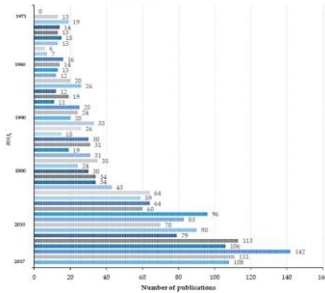
Palliative Care Delivery in the NICU: What Barriers Do Neonatal Nurses Face?

Victoria J. Kain, RN, NCC, MN

PALLIATIVE CARE IS A WELL-ESTABLISHED AND INTEGRAL part of contemporary adult health care provision. **C**ullin and Carter describe neonatal palliative care as holistic and extensive care for babies who are not expected to survive. This care should be provided in an environment where the baby's suffering can be prevented and relieved and where conditions for the baby's living and dying are optimal. In a 2002 commentary, Glacken and Merenstein stated that 20,000 babies born in the U.S. each year had conditions incompatible with life and were essentially "born dying." This suggests that palliative care in neonatology is highly relevant, yet palliative care principles are inconsistently applied. This inconsistency may evolve from the historical association of palliative care with oncology.

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PUBMED NEONATAL PALLIATIVE CARE CITATIONS: 1971 - 2017



Increasing publications are addressing neonatal palliative care



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A Neonatal PC model of care – but who benefits?

- The five leading causes of infant death (descending order) are:
 1. congenital malformations, deformations, and chromosomal abnormalities (1/5 of deaths)
 2. Low gestation and low birthweight;
 3. sudden infant death syndrome (SIDS);
 4. newborns affected by maternal complications of pregnancy; and
 5. newborns affected by complications of placenta, cord, and membranes.



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Why is neonatal PC conceptually difficult?

- The terms ‘palliative care’ and ‘newborn’ sit uncomfortably side by side.
- For health care professionals dealing with neonates, it may be difficult to step away from a **heroic model of care** to a **holistic symptom-based approach**, with the **loss of optimism and hope** that this implies.



(de Rooy, Aladangady, & Aidoo, 2012)



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Primum non nocere

- Confusion exists about what palliative care is, and when – if ever – it is appropriate to withhold ‘aggressive’, curative treatment?
- Ethical principles interplay:
 - First, do no harm (*Primum non nocere*) - or **non-maleficence**.
 - Veracity: ‘truth telling’;
 - Advocacy: the neonatal population is extremely vulnerable (a ‘voiceless’ population).



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Can death ever be 'good'?

- The palliative care literature talks about 'good death' and 'bad death';
- We know that when death is inevitable, it can be 'bad' or it can be 'good';
- A study published in the 'American Journal of Geriatric Psychiatry' identified core themes associated with dying well, and some of these themes related to neonates.



(Meier et al.)



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Our response:

"The goal, therefore, is to facilitate a so-called 'good death'."

A 'good death' is defined as one that is '... free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards"

(Institute of Medicine of the National Academies, 2003, p.39).

Neonatal palliative care in action: moving beyond the rhetoric and influencing policy

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Abstract
The purpose of this paper is to move beyond the rhetoric of espousing the importance and timeliness of palliative care for the neonatal population, and to explore how what is known can influence health and social policy. A recent Commonwealth of Australia Senate enquiry into palliative care raised concerns about the current lack of specialist perinatal and neonatal palliative care in Australia. Inherent to the difficulties of moving a neonatal palliative care model forward are the identified barriers to palliative care practice in the clinical setting, which have been well defined. To reform policy, it is imperative that health professionals in the neonatal discipline are knowledgeable about legislative priorities and the public concerns regarding palliative care for neonates. This paper argues that there are several priorities for moving this model of care forward, which include legislation that supports access to care such as development and funding support of perinatal hospices, continuity of care, caregiver support, research and in particular education for the health care professionals caring for dying babies and their families. To achieve this, we need to set national research priorities that reflect a truly collaborative partnership. It is time to move beyond the rhetoric.

Journal of Research in Nursing
ISSN 1448-0885
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sagepub.com/journalsPermissions.nav
DOI: 10.1177/1448088515268102
jrn.sagepub.com
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... and why is it so challenging? The rhetorical questions.

- The When
when will it happen? have we got time to make decisions?
- The Who
Who will be involved, and how? How is the nurse involved?
- Managing uncertainty
what is the baby survives post extubation for example? what if there is hope? what if we are 'giving up' too early?
- Joint planning for survival
How will the baby go home? is that even feasible?
- Supporting wishes for place of care
If the family take the baby home, how will that work?
- Encouraging the 'scary leap' out of NNU
Freedom, abandonment, autonomy?
- Having 'That' talk
what if we're not 'on the same page', what if the parents are mad at us?
- Our own feelings and beliefs
"I'm not comfortable with this" "this isn't right" "why are the parents making us do this?" "I can't work here anymore" "this is torture"
- Empowering parents & offering choice
What do parents want/need to know?
- Practical challenges
Legally, can we do this?



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2020: Time to redefine NPC

Christine A. Fortney, PhD, RN - Section Editor
Special Series: Palliative Care

Conceptually Redefining Neonatal Palliative Care

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ABSTRACT
Background: First defined in 2002 by Carter and Carter, neonatal palliative care (NPC) is a relatively new model of care in neonatal medicine, first appearing in the medical literature in the early 1980s.
Purpose: The purpose of this article is to suggest a conceptual definition of NPC that encompasses all the essential concepts as a new of moving NPC forward through a conceptual approach.
Methods: Following a review of the NPC literature, a thematic analysis as a method for identifying, analyzing, and integrating patterns of meaning in the adolescents ("Patients") within the literature was undertaken.
Findings: The major themes identified included philosophies of care, support, culture and spirituality, the team, and limitations for resources. As the team of NPC is the primary of maintaining quality of life, while providing ethical and humane care that supports a "good death." The alternative elements presented in this article are considered essential to a comprehensive and conceptual definition of NPC presented here.
Key Words: comfort care, neonatal end-of-life care, neonatal palliative care, perinatal palliative care

Palliative care options for neonates are necessary due to neonates having the highest death rate in the pediatric population,¹ with prematurity cited as the leading cause of death. Palliative care for neonates may be appropriate for those born in the following circumstances: antenatal diagnosis of a life-limiting condition; neonates born at the margin of viability; neonates diagnosed with a life-

this method had its limitations and helping them to understand that palliative care might be an option was summarily dismissed as "neonates that neonates" for the neonatologist. With this article, however, an integrated approach to palliative care for the "hopelessly sick newborn" was proposed perhaps for the first time, focusing on the areas of decision-making, the physical environment, family involve-

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NPC redefined

Abridged:

- NPC is an **active** and **holistic** approach that is an integral component of the neonatal care delivery model.
- This **active form of care** begins before, at, or after birth once a life-limiting, terminal, or uncertain condition has been determined.
- It involves a purposeful and planned treatment approach that involves the multidisciplinary team and shared decision-making with the family.



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Practical Advice – Parents & Families

Helpful words

"I wish things were different"
 "I hope he gets better, too..., but I think it is very unlikely"
 "We have tried everything that might help and unfortunately, he is too sick to respond. Perhaps we need to consider alternative goals of care"
(anger can be the most difficult emotion to manage)
 Saying the following can help address/normalize parental emotions:
 "I can see you are angry; many parents feel this way."
 Asking parents if they want the team to leave and come back later is often helpful.
 Sometimes, parents do not want to engage in conversations, others do not want to hear about "scary statistics," and others can also cry for a prolonged period.



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Practical Advice – Non-Pharm management

Pain is common at the end of life.

- The neonate should be assessed regularly using a *validated pain assessment tool* and the appropriate management initiated
- Non-pharmacological management should be implemented including *developmental care, swaddling, reducing noise and sound stimuli, non-nutritive sucking, massage and positioning, pressure area care with the use of an air mattress, gel pillows, skin care, mouth care, basic hygiene, warm wraps, human contact and skin-to-skin contact should continue.*



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Facilitating healthy attachment and grieving

- Address the newborn by name
- Provide suggestions for talking with children and/or family
- Provide opportunity for family to be with, hold, bathe, and dress the infant
- Help to create lasting memories (footprints, molds, pictures, audio recordings of baby's heartbeat during labor, or noises if born alive, lock of hair, crib card, ID bands, beads, memory box or scrapbook, baby's clothes or blankets)
- Incorporate opportunity for family cultural and religious rituals or ceremonies into the care plan
- Offer lactation-suppression information and support
- Provide connection to support groups, bereavement counseling, resources, and hospice, as necessary



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Finally – the controversy of feeding

- The goal of feeding is to **reduce distress from hunger and provide comfort**
- The **benefits versus risks** of feeding should be weighed when considering initiating or withholding feeds.
- Oral feeds should only be withheld if it is **believed that the feeds are causing pain or discomfort**, or the neonate is **at risk of aspiration**
- If the **neonate is demanding feeds**, breastfeeding, bottle or small volumes of nasogastric feeds should be offered for comfort.
- If vomiting is an issue, the feed volume should be reduced.
- The administration of parenteral/enteral nutrition/hydration is **rarely indicated** as it is considered a medical form of life support
- If the duration between the transition to a palliative approach to care and death is expected to be short, it is reasonable to cease feeds and stop intravenous hydration if it is felt that feeding could cause distress.
- When withholding feeds is indicated, the family needs to be reassured that this is done in the best interest of the neonate



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The Mayfly

A mayfly flies
 In May or June.
 Its life is over
 Far too soon.
 A day or two
 To dance,
 To fly—
 Hello,
 Hello,
 Good-bye,
 Good-bye.



by Douglas Florian



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