

# AN INTERNATIONAL OVERVIEW OF PERINATAL PALLIATIVE CARE DEVELOPMENT

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# OUTLINE

- Define Perinatal Palliative Care (PPC)
- List International Programs
- Neonatal Comfort Care Program (NCCP) at Columbia University, New York



# PERINATAL PALLIATIVE CARE

## 1. PRE-NATAL

- Plan of care offered to women electing to continue their pregnancy with fetal diagnosis of life-limiting or life-threatening condition
- Preparation of post-natal plan(s) of care for the baby

## 2. NEONATAL

- Neonatal plan of care based on diagnosis, prognosis and family's preference.
  - Comfort care: end of life stage
  - Palliative care: supportive relationships with families whose infants are admitted to the NICU receiving limited interventions or intensive care



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 Macauley, MD and the Society for Maternal-Fetal Medicine's liaison member Steven J. Ralston, MD, MPH.*

## Perinatal Palliative Care

### STATEMENT OF ENDORSEMENT

American Academy  
of Pediatrics



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## Perinatal Palliative Care

The American Academy of Pediatrics has endorsed the following publication: American College of Obstetricians and Gynecologists. Perinatal Palliative Care. Committee Opinion No. 786. Washington, DC: American College of Obstetricians and Gynecologists; 2019. Available at: <https://www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Ethics/Perinatal-Palliative-Care>.





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## ACOG COMMITTEE OPINION SUMMARY

### Perinatal Palliative Care

**ABSTRACT:** Perinatal palliative care refers to a coordinated care strategy that comprises options for obstetric and newborn care that include a focus on maximizing quality of life and comfort for newborns with a variety of conditions considered to be life-limiting in early infancy. With a dual focus on ameliorating suffering and honoring patient values, perinatal palliative care can be provided concurrently with life-prolonging treatment. The focus of this document, however, involves the provision of exclusively palliative care without intent to prolong life in the context of a life-limiting condition, otherwise known as perinatal palliative comfort care. Once a life-limiting diagnosis is suspected antenatally, the tenets of informed consent require that the pregnant patient be given information of sufficient depth and breadth to make an informed, voluntary choice for her care. Health care providers are encouraged to model effective, compassionate communication that respects patient cultural beliefs and values and to promote shared decision making with patients.

Review

# Pediatric Palliative Care in Infants and Neonates

Brian S. Carter<sup>1,2,3</sup>

## PUBMED NEONATAL PALLIATIVE CARE CITATIONS: 1971 - 2017

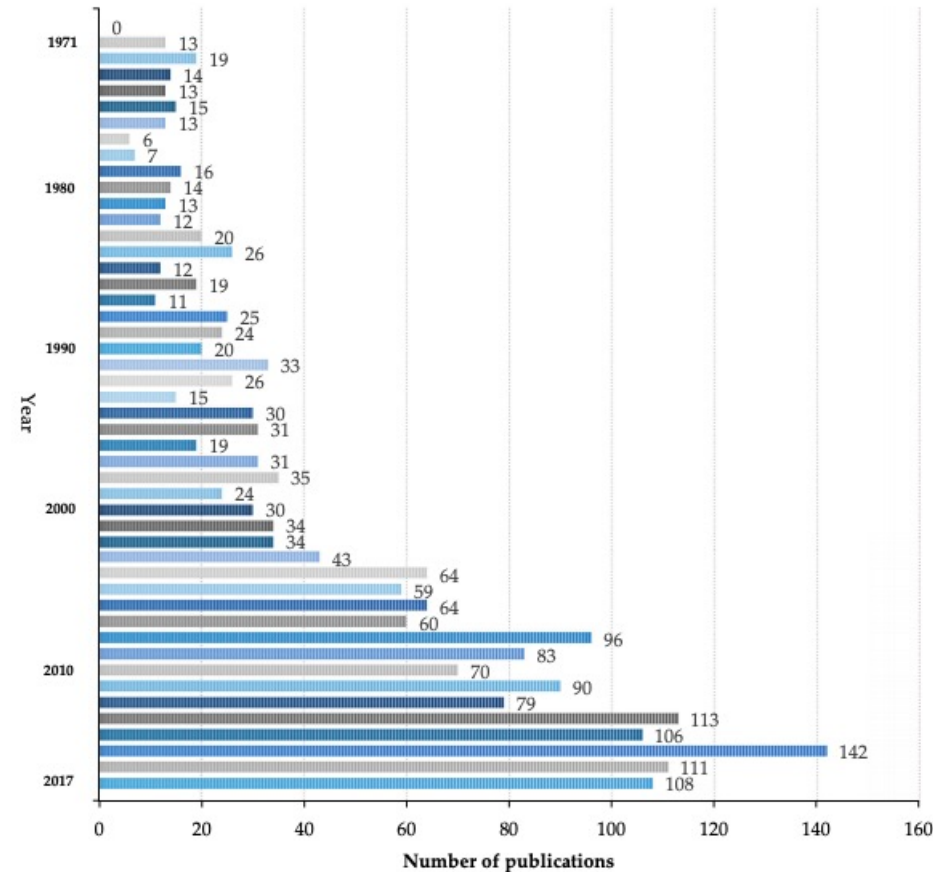
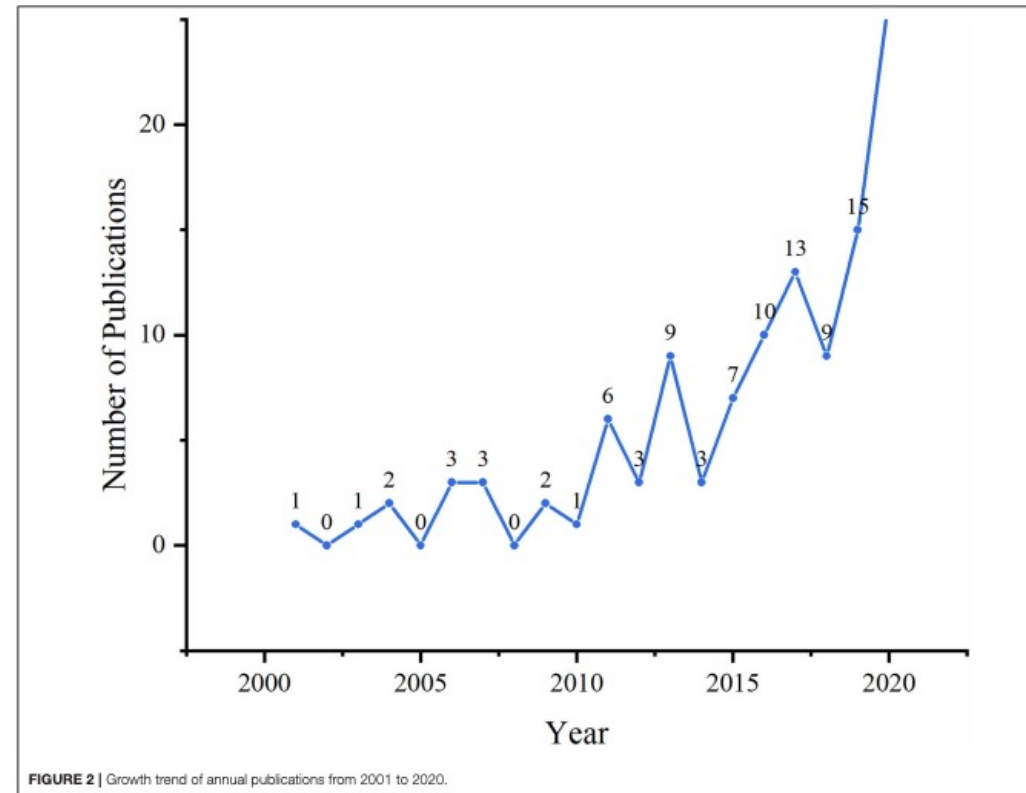


Figure 1. Increasing publications addressing neonatal palliative care.



# Bibliometric Analysis of Global Research on Perinatal Palliative Care

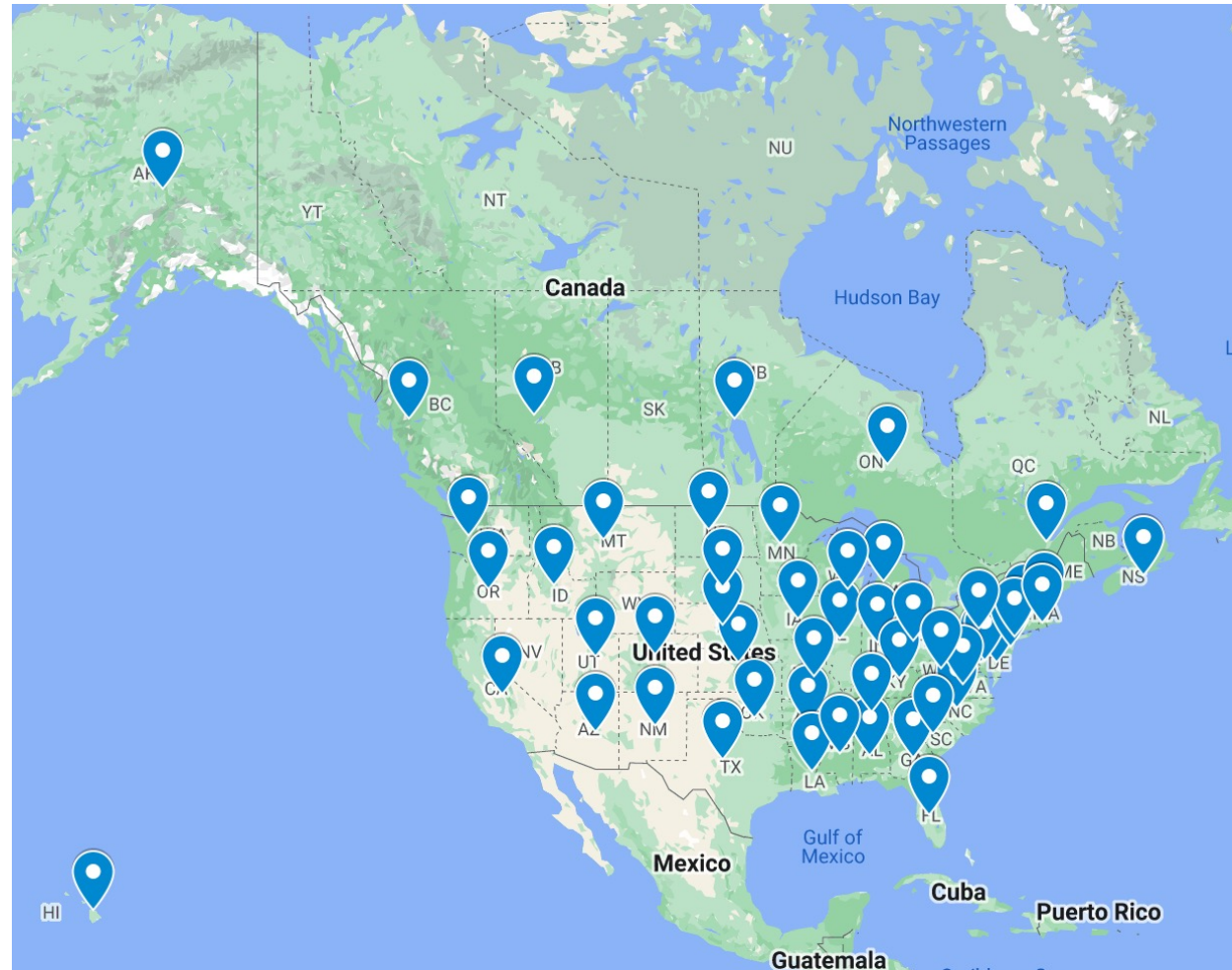
Yiting Wang<sup>1†</sup>, Chunjian Shan<sup>1†</sup>, Yingying Tian<sup>2</sup>, Congshan Pu<sup>1</sup> and Zhu Zhu<sup>3\*</sup>





# PROGRAMS IN NORTH AMERICA

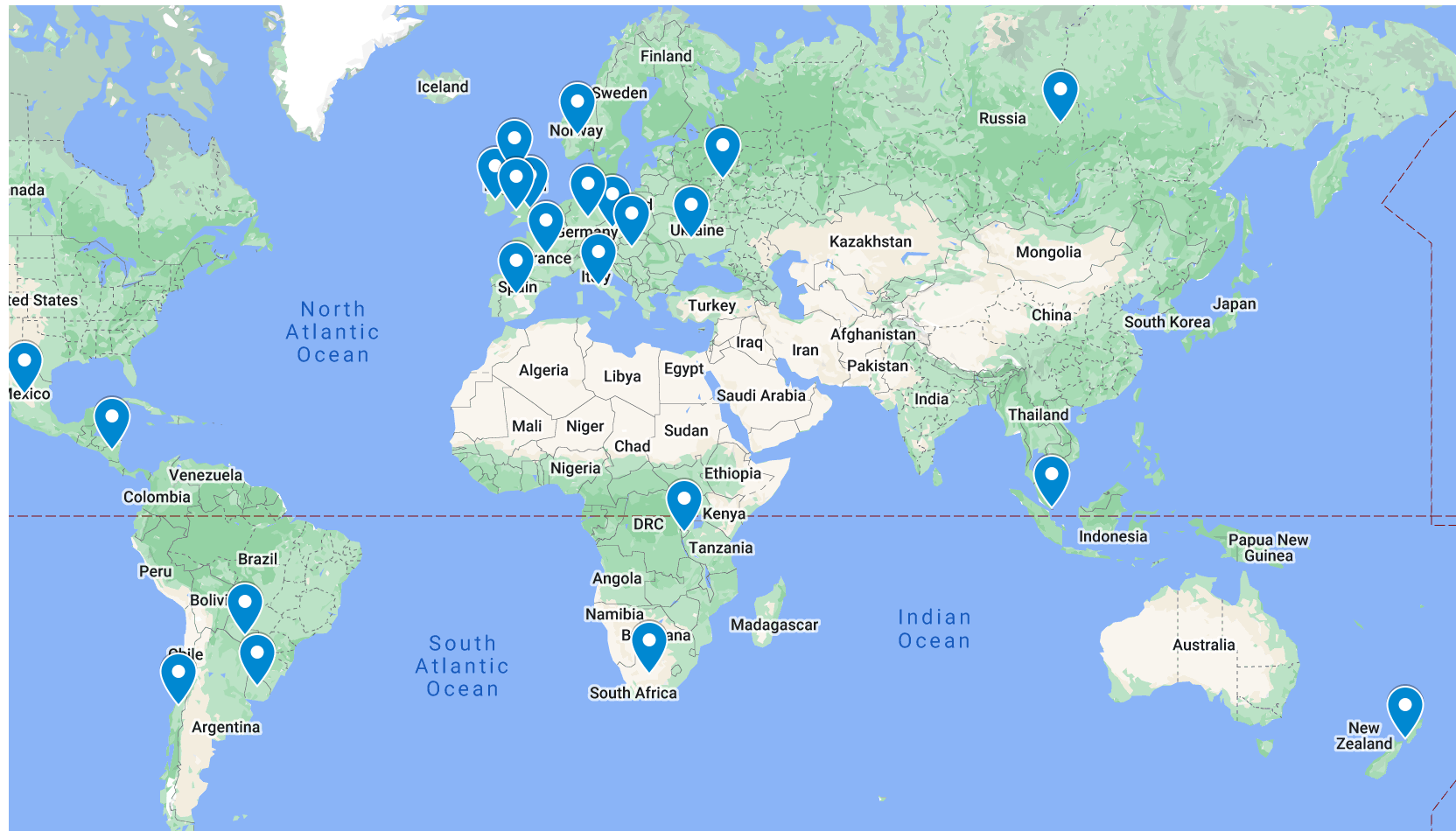
[www.perinatalhospice.org](http://www.perinatalhospice.org)





# PROGRAMS IN THE WORLD

[www.perinatalhospice.org](http://www.perinatalhospice.org)



# THE NEONATAL COMFORT CARE PROGRAM

- **MISSION:** The NCCP **honors the lives of babies with life-limiting conditions** by creating a safe and loving space for bonding, attachment, comfort and joy for them and their families along the perinatal journey.
- **VISION:** The NCCP is also committed **to teaching and research**, so that **our specialized approach will become the standard of care around the world** for any baby with life-limiting conditions.



# NCCP – CORE TEAM



## CORE TEAM

- Medical Director
- 2 Nurses
- Social Worker
- Program Manager

## NICU COLLABORATORS

- Speech Pathologist / Lactation Consultant
- Psychologist
- Child Life
- Chaplain

## OB/MFM COLLABORATORS

- Physicians
- Nurses

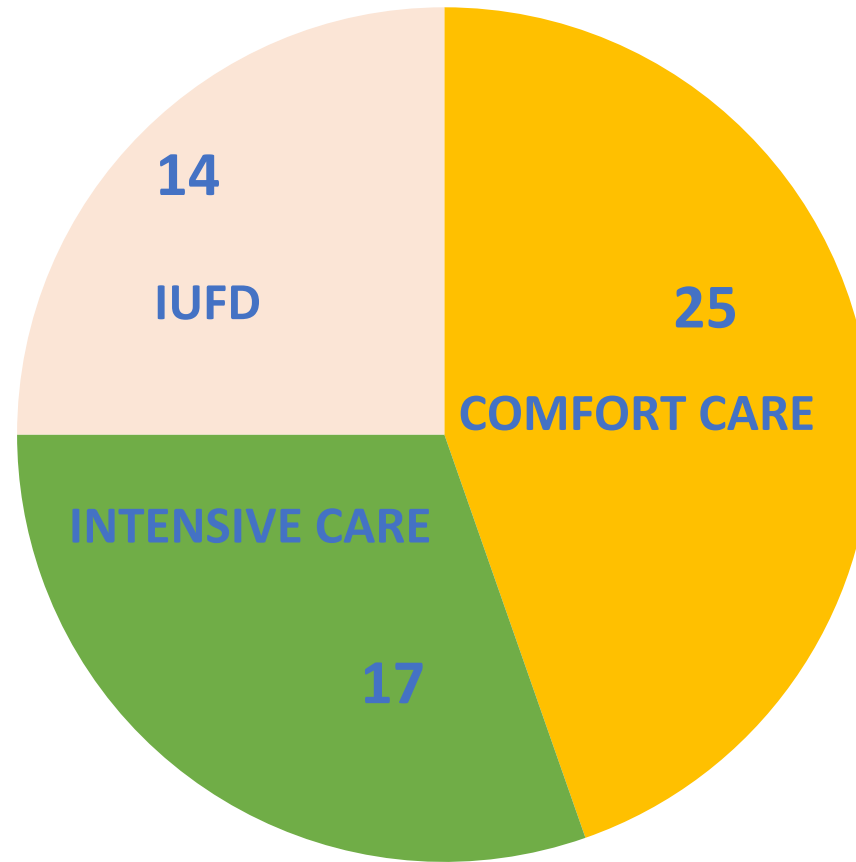


# 2021 – CASES (56 pregnancies/~150 encounters)

- 15 Trisomy 18
- 5 Trisomy 13
- 6 Renal agenesis/dysplasia
- 6 other (unknown syndromes)
- 5 CHD (2 HLHS, 1 HRH, 2 pentalogy of Cantrell)
- 4 TTTS with extreme IUGR of 1 twin
- 4 Severe Hydrops
- 3 CNS anomalies (lissencephaly, zig/zag brainstem + hydro, arthrogryposis)
- 2 Limb-body-wall Syndrome
- 6 Pre/peri-viable (= or <22 weeks GA)



# OUTCOMES IN 2021



# PRENATAL CONSULTS

- REFERRAL BY MFM/OB
- PRENATAL CONSULT WITH TEAM
- DOCUMENTATION ON EMC
- WEEKLY ROUNDS WITH TEAM
- WEEKLY LIST TO NICU + OB PROFESSIONALS



# DELIVERY – POSTNATAL COURSE

- MENTORING IN DELIVERY ROOM
- PRIMARY CARE OF THESE INFANTS IN DELIVERY ROOM / POST-PARTUM, NOT IN THE NICU
- FOCUS ON BONDING AND COMFORT





# CULTURE CHANGE

‘NICU problematic bonding’ vs ‘POST-PARTUM limitless bonding’



# ACHIEVING A STATE OF COMFORT

1. BONDING
2. MAINTENANCE OF BODY TEMPERATURE
3. RELIEF OF HUNGER AND THIRST
4. ALLEVIATION OF DISCOMFORT AND PAIN

*Parravicini E. Curr Opin Pediatr, 2017*



# ALLEVIATION OF DISCOMFORT AND PAIN

## NON-PHARMACOLOGICAL STRATEGIES

- SKIN-TO-SKIN
- HOLDING
- GENTLE SUCTIONING
- COLOSTRUM CARE/ORAL SUCROSE
- BREAST/BOTTLE FEEDING & OTHER DEVICES

## PHARMACOLOGICAL TREATMENT

- Acetaminophen PO/PR
- Morphine Sulfate PO
- Fentanyl IN (intra-nasal)
- Lorazepam PO
- Midazolam IN

# REDIRECTION OF GOAL OF CARE IN NICU/PICU

- 34 weeks F/C, trisomy 18
- CHD: coarctation, large VSD
- Full intervention for 'precious time at home'
- S/p coarct repair and PA banding
- Several admissions to PICU for resp crises
- 'Poor quality of life'
- Transition to Hospice care @ home
- She died at 4 months @ home

# PALLIATIVE CARE AS SUPPORT

- Prenatal diagnosis of trisomy 18
- Full intervention
- NICU d/c @ 15 days with O2 by NC
- Several admissions to PICU for resp crises
- Transition to palliative care?
- S/p PDA ligation but NOT trach
- No more respiratory crises
- She is 9 and well

# GUIDELINES AND POLICY

## Guidelines

- *Parravicini E, McCarthy F. Comfort in Perinatal and Neonatal P.C. Chapter 4. Handbook of Perinatal and Neonatal Palliative Care, Springer Publishing, 2020*

## Nursing Policy – Nursing Care in Perinatal/Neonatal Loss

- This policy provides best practice to OB, Antepartum, Postpartum and NICU nurses caring for babies born with life-limiting conditions, pre-viable, stillborn, or have had a redirection of care and how to support their families



# Parental assessment of comfort in newborns affected by life-limiting conditions treated by a standardized neonatal comfort care program

E Parravicini<sup>1</sup>, M Daho<sup>2</sup>, G Foe<sup>3</sup>, R Steinwurtzel<sup>1</sup> and M Byrne<sup>4</sup>

**OBJECTIVE:** To assess the perception of parents concerning the state of comfort maintained in their infants born with life-limiting conditions and treated by a standardized neonatal comfort care program.

**STUDY DESIGN:** Participants were parents ( $n=35$  families) who elected comfort care for their newborns diagnosed with life-limiting conditions. Standardized comfort measures including family/infant bonding, warmth, nutrition/hydration and pain/discomfort management were provided to all infants. Parents consented to receive a questionnaire with quantitative response options and open-ended questions.

**RESULTS:** Forty-two questionnaires (26 from mothers and 16 from fathers) were collected and analyzed. Most parents reported that their child was treated with respect, in a caring, peaceful and non-invasive environment. To the question 'Do you think that overall your baby received comfort' mode response was 'always'.

**CONCLUSION:** Parents of infants with life-limiting conditions perceive that their babies experience comfort as a result of the care provided by the standardized Neonatal Comfort Care Program.

*Journal of Perinatology* advance online publication, 19 October 2017; doi:10.1038/jp.2017.160



## Neonatal Palliative Care for Complicated Cardiac Anomalies: A 10-Year Experience of an Interdisciplinary Program at a Large Tertiary Cardiac Center

Caitlin Haxel, MD<sup>1,2,\*</sup>, Julie Glickstein, MD, FAAP<sup>2</sup>, and Elvira Parravicini, MD<sup>2</sup>

**Objectives** To report the outcomes of a Neonatal Palliative Care (NPC) Program at a large tertiary cardiac center caring for a subset of fetuses and neonates with life-limiting cardiac diagnoses or cardiac diagnoses with medical comorbidities leading to adverse prognoses.

**Study design** The Neonatal Comfort Care Program at New York-Presbyterian Morgan Stanley Children's Hospital/Columbia University Medical Center is an interdisciplinary team that offers the option of NPC to neonates prenatally diagnosed with life-limiting conditions, including single ventricle (SV) congenital heart disease (CHD) or less severe forms of CHD complicated by multiorgan dysfunction or genetic syndromes.

**Results** From 2008 to 2017, the Neonatal Comfort Care Program cared for 75 fetuses or neonates including 29 with isolated SV CHD, 36 with CHD and multiorgan dysfunction and/or severe genetic abnormalities, and 10 neonates with a prenatal diagnosis of isolated CHD and postnatal diagnoses of severe conditions who were initially in intensive care before transitioning to NPC because of a poor prognosis.

**Conclusions** At New York-Presbyterian Morgan Stanley Children's Hospital/Columbia University Medical Center, a large tertiary cardiac center, 13.5% of parents of fetuses or neonates with isolated SV CHD opted for NPC. Twenty-six of 29 newborns with SV CHD treated with NPC died. Of the remaining, 2 neonates with mixing lesions are alive at 3 and 5 years of age, and 1 neonate was initially treated with NPC and then pursued surgical palliation. These results suggest that NPC is a reasonable choice for neonates with SV CHD. (*J Pediatr* 2019;■:1-10).



# Early palliative care reduces stress in parents of neonates with congenital heart disease: validation of the “Baby, Attachment, Comfort Interventions”

Katharine Callahan<sup>1,3</sup> • Rochelle Steinwurtzel<sup>1</sup> • Lyn Brumarie<sup>2</sup> • Sarah Schechter<sup>1</sup> • Elvira Parravicini<sup>1</sup>

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## Abstract

**Objective** To test our hypothesis that an innovative method of early palliative care called “Baby, Attachment, Comfort Interventions” reduces psychological distress in parents of neonates with congenital heart disease.

**Study design** Prospective cohort study of parents of neonates with congenital heart disease. Distress was evaluated at admission and discharge using Neonatal Unit Parental Stressor Scale and Depression Anxiety Stress Index-21. Control parents received standard of care. Intervention parents received interdisciplinary interventions aimed at improving neonatal comfort and parenting experience.

**Results** Seventy-seven parents participated. Stress decreased in the intervention group (26 parents) but not in the control group (51 parents). There was no decrease in anxiety or depression in either group.

**Conclusion** Early palliative care reduces stress in parents of neonates with congenital heart disease. Further work is needed to address depression/anxiety in this group of high-risk parents.



Fig. 1 Logo for the BACI method. Copyright© 2019

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# LEARNING OBJECTIVES

1. **Identify the essential elements of prenatal and neonatal palliative consult**
2. **Describe pregnancy and delivery management with fetal diagnosis of life-limiting condition when mothers elect to continue the pregnancy**
3. **Identify newborns' basic needs and apply strategies to successfully achieve a state of comfort for newborns with life-limiting conditions**
4. **Identify families' needs and apply strategies to successfully achieve support when they have a newborn with a life-limiting condition**





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THANKS!

QUESTIONS?