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NEONATAL
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THE NEONATAL COMFORT CARE PROGRAM: SHARING 20 YEARS OF EXPERIENCE

Aarau, May 19, 2026

Elvira Parravicini, MD

Professor of Pediatrics

Director, Neonatal Comfort Care Program

Columbia University Irving Medical Center, New York, NY

OUTLINE

1. Perinatal Palliative Care

- Definition
- Components
- Candidates

2. NCCP experience over 20 years

- Patients
- Outcomes

PERINATAL PALLIATIVE CARE: DEFINITION

Plan of care for women who elect to continue the pregnancy with a fetal diagnosis of life-limiting condition and for their babies



PERINATAL PALLIATIVE CARE: A NEW OPTION

1. Full intervention for the baby after birth
2. Termination of pregnancy
- 3. Perinatal Palliative care**



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2019 ACOG and AAP RECOMMENDATION



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



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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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.

PERINATAL PALLIATIVE CARE: COMPONENTS

- Multidisciplinary team
- Perinatal journey

Wool & Parravicini, Front Pediatr 2020



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PERINATAL PALLIATIVE CARE: COMPONENTS

- Multidisciplinary team

MEDICAL TEAM

- Obstetrician/MFM
- Neonatologist
- Consultive services (cardiology, surgery, genetics, etc.)

SUPPORTIVE TEAM

- Nurse coordinator
- Midwife
- Social worker
- Psychologist
- Chaplain
- Child Life

Wool & Parravicini, Front Pediatr 2020



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PERINATAL PALLIATIVE CARE: COMPONENTS

- Perinatal journey
 - Prenatal counseling
 - Pregnancy care
 - Labor and delivery
 - Neonatal plan of care
 - Disposition
 - Bereavement after loss (short and long term)

Wool & Parravicini, Front Pediatr 2020



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THE PRENATAL PALLIATIVE CONSULT

Preparation of the plan of care:

- Diagnostic and prognostic certainty
 - Review prenatal findings and discussion with providers
 - Up-to-date medical info and honesty regarding wide range of outcomes
 - Improving outcomes associated with more aggressive care
- Prognostic meaning to the family

Leuthner, Clin Perinatol 2004; Janvier, 2012; Mendez, 2016; Lantos, 2017; Marty, 2018



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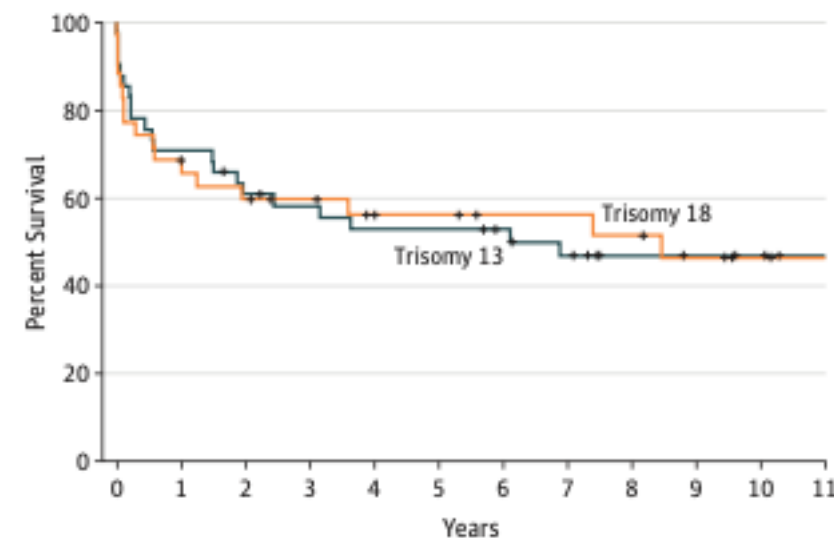
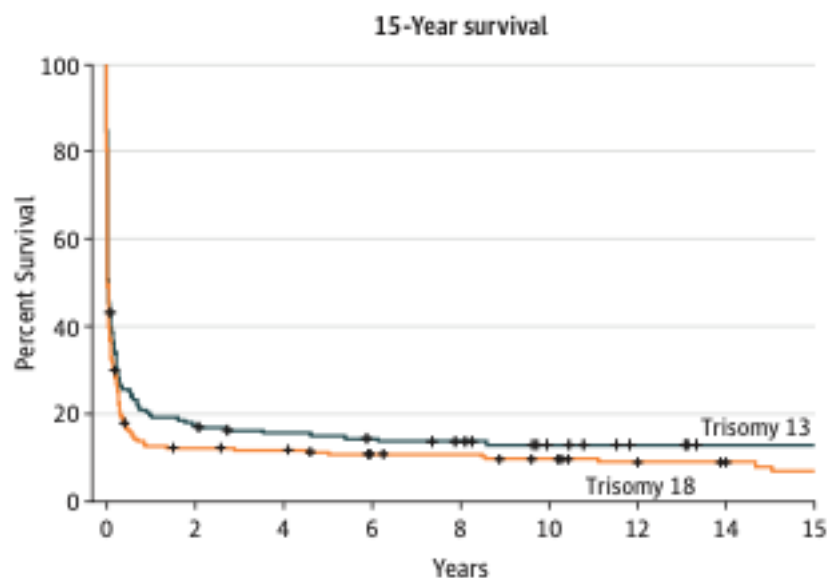
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Survival and Surgical Interventions for Children With Trisomy 13 and 18

Katherine E. Nelson, MD; Laura C. Rosella, PhD; Sanjay Mahant, MD; Astrid Guttman, MDCM

Figure 2. Survival After First Surgery and Number at Risk Among Children With Trisomy 13 and 18 Undergoing Surgeries



JAMA 2016

THE PRENATAL PALLIATIVE CONSULT

Preparation of the plan of care:

- Diagnostic and prognostic certainty
- Prognostic meaning to the family
 - Identify parents' view on prognosis
 - Respect choice "*to give a chance*"
 - Cultural and spiritual differences

Guon, 2014; Janvier, 2016; Carter, 2018; Weaver, 2020; Janvier, 2020



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PARENTS VIEW ON DIAGNOSIS



Guon, Am J Med Genetics 2013



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THE CONSULT – ESSENTIAL STEPS

1. Build a relationship of trust
2. Prognostic awareness
3. Offer diagnosis & prognosis
4. Identify what is important to the family
5. Offer options for different plans of care



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CANDIDATES

- Life-limiting conditions
- Complex medical condition with potential adverse outcome



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CANDIDATES

- Life-limiting conditions

Expected early demise (CC is the only choice)

- Renal agenesis
- Anencephaly
- Limb-body-wall syndrome



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CANDIDATES

- Life-limiting conditions

Burden of intensive care may exceed benefit:

- Trisomy 13 or 18 or other severe genetic syndromes
- Complex cardiac conditions (Single ventricle complicated with other anomalies)
- Severe brain anomalies (Lissencephaly, alobar holoprosencephaly)
- Extreme prematurity at the cusp of viability

CANDIDATES

- Life-limiting conditions

Conditions associated with lung hypoplasia:

- Severe or bilateral CDH
- Severe skeletal anomalies
- Bilateral renal dysplasia, ARPKD, LUTO
- Severe hydrops



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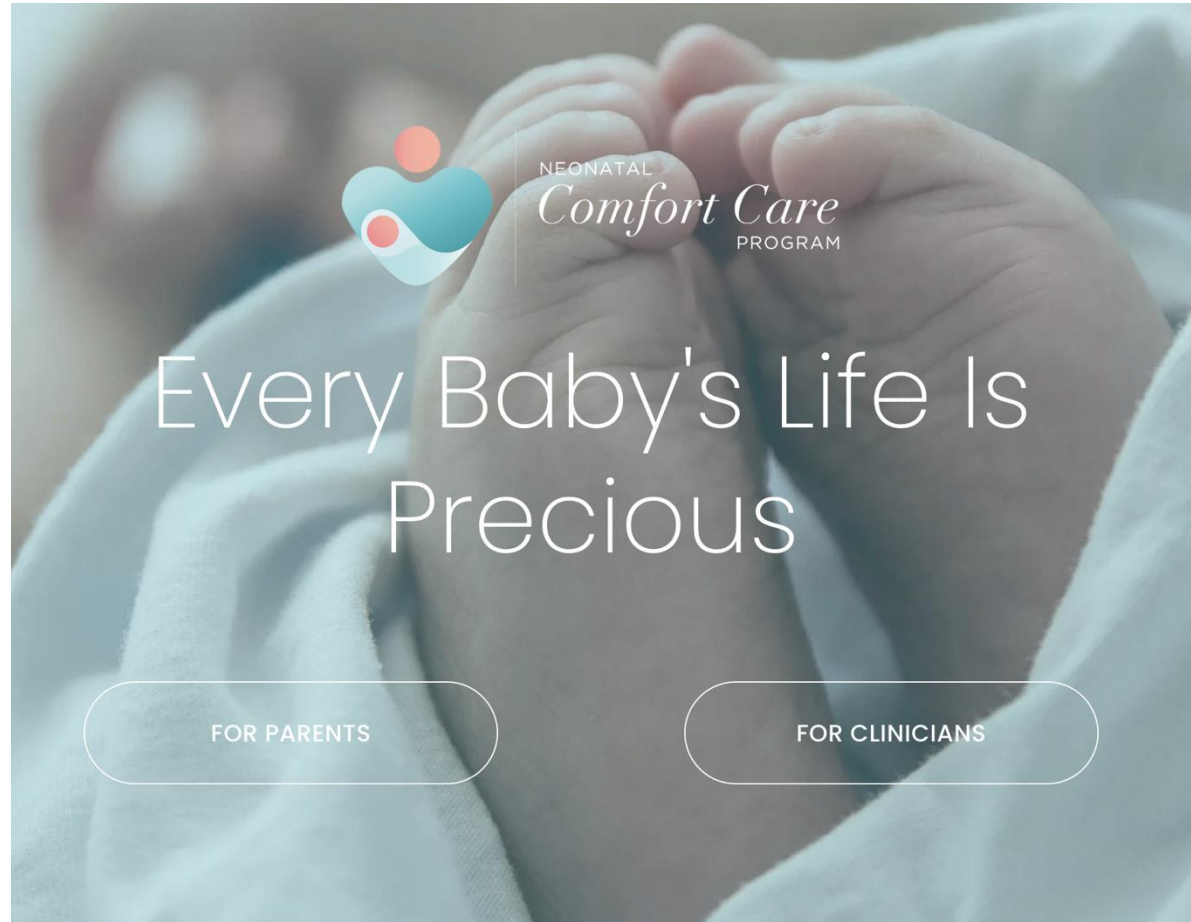
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The Neonatal Comfort Care Program (NCCCP)



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NCCP team



Elvira Parravicini



Sinead Brady

Bryn McNamee-Tweed



Sarah Fahrenthold



Frances McCarthy

Rochelle Steinwurtzel



2025 – 76 CASES

18 Trisomy 18 and 13

16 Renal (agenesis, severe dysplasia or LUTO + pulmonary hypoplasia)

13 CNS anomalies (exencephaly, lissencephaly, alobar holoprosencephaly, brain tumor, severe ICH)

9 CHD (SV + TAPVR, SV + heterotaxy, SV + genetic, cardiomyopathy)

7 other (multiple anomalies)

6 severe skeletal dysplasia

4 Severe Hydrops

3 Pre/peri-viable (<22 weeks GA)



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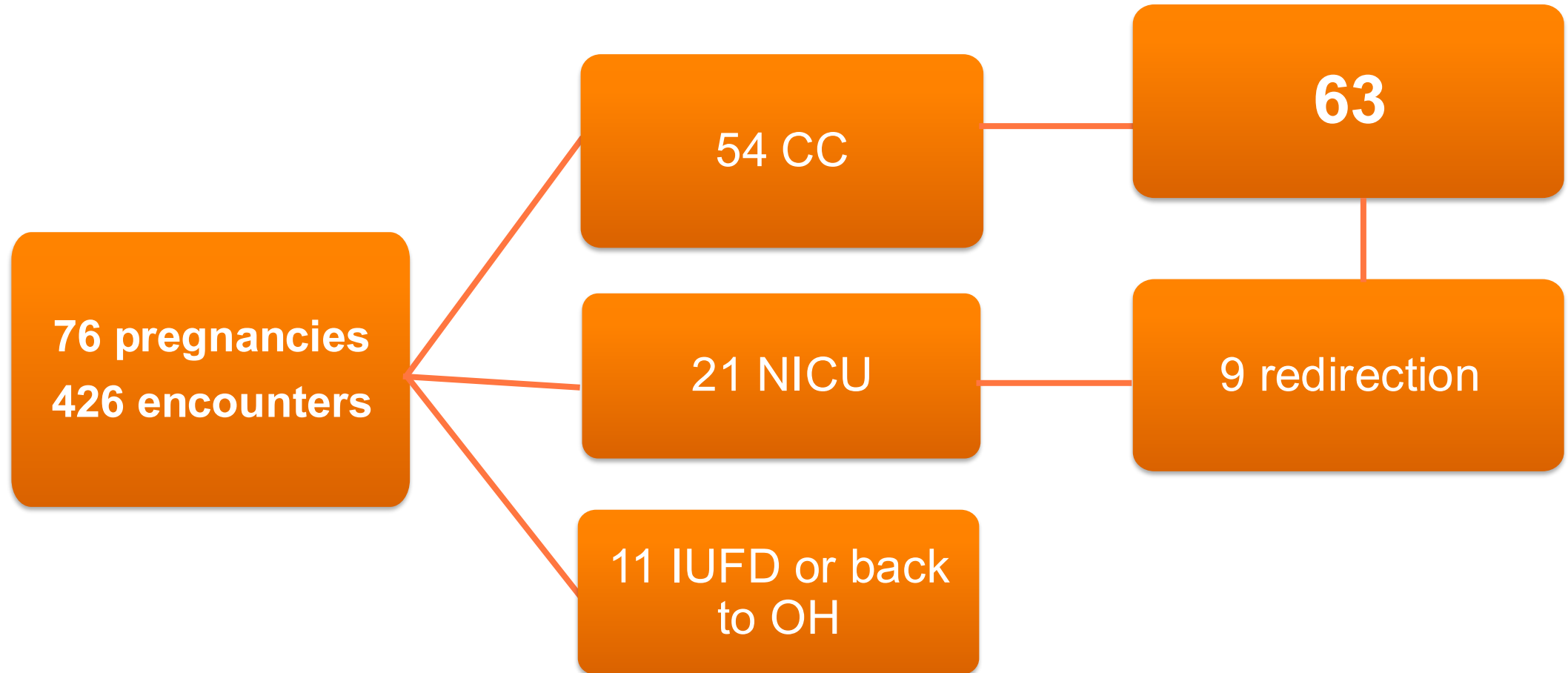
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2025 PATIENTS & OUTCOMES



NCCP experience

- Comfort and alleviation of distress/pain
- Trisomy 13/18
- Complex CHD



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NCCP experience

- Comfort and alleviation of distress/pain
- Trisomy 13/18
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NCCP experience – COMFORT



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Perinatal palliative care: focus on comfort.
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Perinatal palliative care: focus on comfort

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Providing comfort while a patient is living with a life-limiting condition or at end of life is the hallmark of palliative care regardless of the patient's age. In perinatal palliative care, the patient is unable to speak for themselves. In this manuscript we will present guidelines garnered from the 15-year experience of the Neonatal Comfort Care Program at Columbia University Irving Medical Center, and how they provide care for families along the perinatal journey. We will describe essential tools and strategies necessary to consider in assessing and providing comfort to infants facing a life-limiting diagnosis *in utero*, born at the cusp of viability or critically ill where the burden of care may outweigh the benefit.



NCCP experience – **COMFORT**

NON-PHARMACOLOGICAL STRATEGIES

- Skin-to-skin
- Holding
- Gentle suctioning
- Colostrum care
- Breast/bottle feeding & other devices

PHARMACOLOGICAL TREATMENTS

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

NCCP experience – **COMFORT**

Thanatophoric Dysplasia

- Skin-to-skin
- Gasping resolved with IN Fentanyl + PO morphine
- Baby peacefully died on mother's arms after few hours

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

E Parravicini¹, M Daho², G Foe³, R Steinwurtzel¹ and M Byrne⁴

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

Table 2. Averaged Likert responses to 24 questions related to infant comfort as perceived by parents

	N	Minimum	Maximum	Mean	s.d.
<i>Items for which higher score means more comfort</i>					
Do you think that the environmental conditions (temperature, light, noises) during your baby's admission were adequate?	42	3	5	4.76	0.532
Do you think that health care workers involved in the care of your baby treated him/her respectfully?	42	3	5	4.86	0.417
Do you think that your baby was treated well by health care workers involved in his/her care?	42	2	5	4.76	0.617
Do you think that the noise level during your baby's admission allowed him/her to rest quietly?	42	2	5	4.88	0.504
Do you think that overall your baby was treated adequately?	42	3	5	4.86	0.417
Do you think that during your baby's admission the environment was comfortable for him/her?	42	4	5	4.88	0.328
Do you think that the level of lighting during your baby's admission allowed him/her to rest quietly?	42	3	5	4.86	0.417
Do you think that health care workers involved in the care of your baby were concerned with obtaining comfort for him/her?	42	4	5	4.88	0.328
Do you think that your baby received comfort and affection from health care workers involved in his/her care?	42	1	5	4.71	0.774
Did you have the opportunity to do Kangaroo Care?	40	1	5	2.3	1.324
Do you think that your baby received adequate treatment for pain and discomfort?	42	2	5	4.71	0.596
Did your baby have opportunity to spend time with you and your family?	42	1	5	4.36	1.358
Did you have the opportunity to show your affection to your baby?	42	1	5	4.62	0.987
Do you think that health care workers involved in the care of your baby were considerate in their interventions with him/her?	42	3	5	4.88	0.395
Do you think that your baby had the opportunity to receive comfort and love from you and from family members?	42	3	5	4.88	0.395
Did you have the opportunity to feed your baby?	42	1	5	1.83	1.102
Do you think that the primary needs of your baby were respected?	42	3	5	4.77	0.520
Do you think that overall your baby received comfort?	42	3	5	4.88	0.395
<i>Items for which lower score means more comfort</i>					
Do you think that there was a lack in health care workers's interventions?	42	1	5	1.38	1.058
Do you think that your baby received too invasive/aggressive medical interventions?	42	1	5	1.46	1.191
Do you think that your baby suffered from cold during the admission?	42	1	5	1.40	0.989
Do you think that your baby suffered from hunger during the admission?	42	1	5	1.55	1.131
Do you think that your baby suffered pain during the admission?	42	1	5	1.86	1.181
Do you think that your baby suffered from thirst during the admission?	42	1	5	1.64	1.206

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COULD YOU DESCRIBE COMFORT CARE WITH A METAPHOR OR AN IMAGE?

... pure love, unadulterated
longing for goodness

Comfort care is like
a hug!

... a band that helps
healing

... an umbrella that
tries to protect
the baby

*... a beautiful calming
corridor between this
world and the next*

NCCP experience

- Comfort and alleviation of distress/pain
- **Trisomy 13/18**
- Complex CHD



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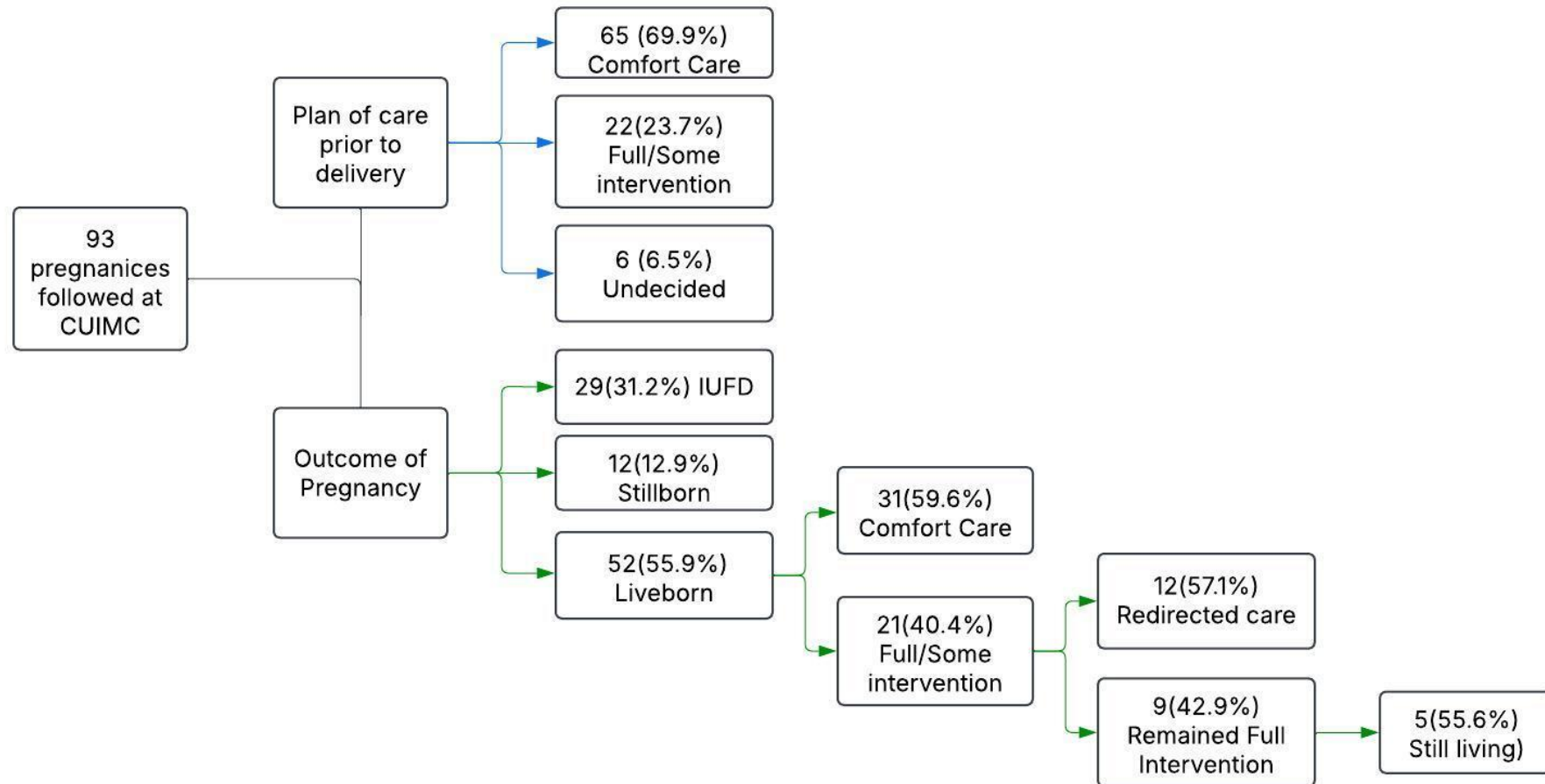
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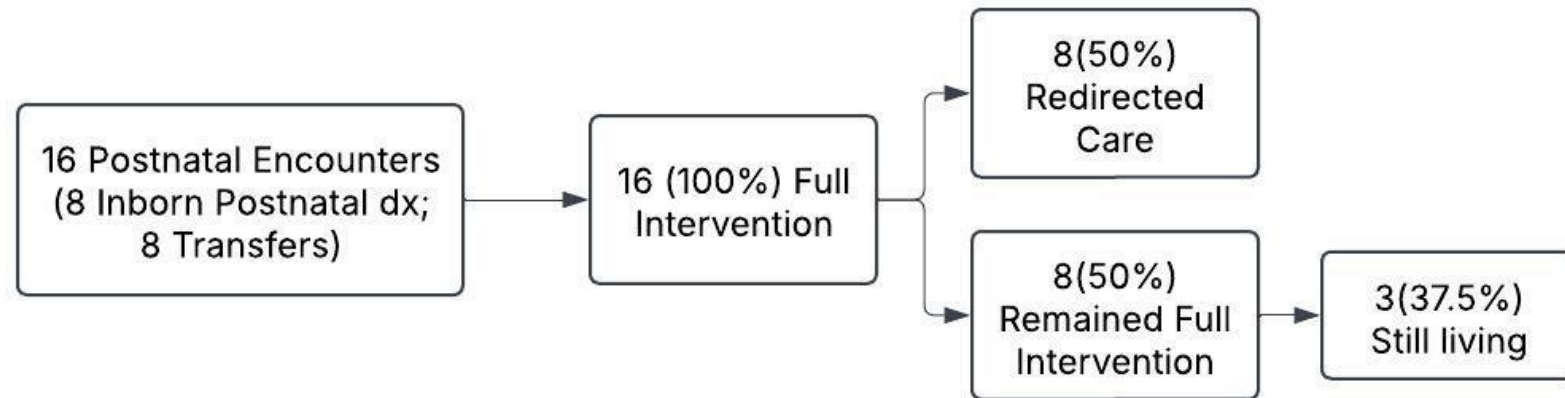
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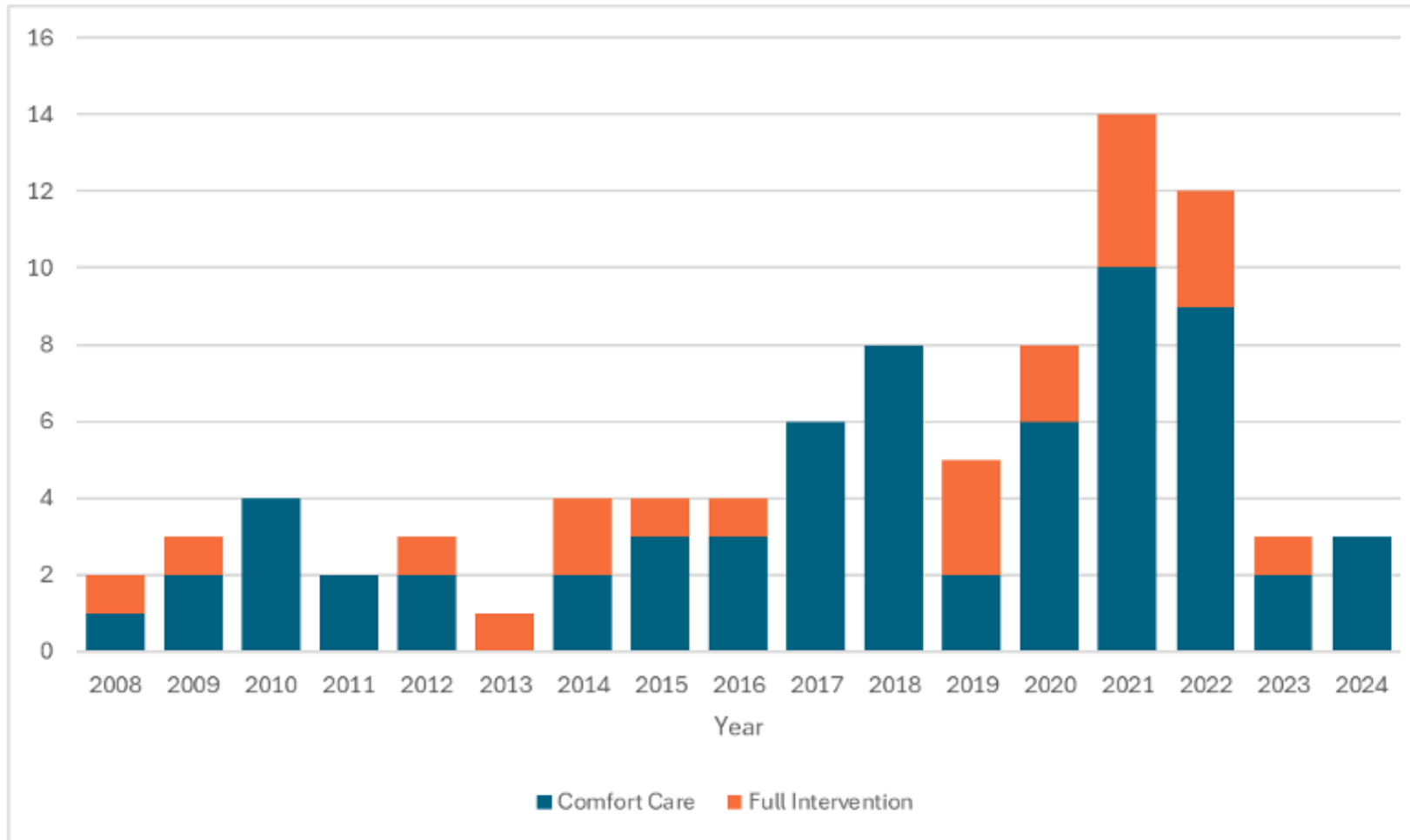
NCCP experience: tri13/18



NCCP experience: **tri13/18**



NCCP experience: tri13/18



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NCCP experience: **tri13/18**

Monitoring During Delivery	30 (37.5%)
Mode of delivery	
C-section	24 (30.0%)
Vaginal	56 (70.0%)

NCCP experience

- Comfort and alleviation of distress/pain
- Trisomy 13/18
- Complex CHD



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

Caitlin Haxel, MD^{1,2,*}, Julie Glickstein, MD, FAAP², and Elvira Parravicini, MD²

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).

LONG-TERM BEREAVEMENT FOLLOW-UP



- Nurses
- Psychologist

NEXT-LEVEL PERINATAL PALLIATIVE CARE TRAINING COURSE

November 4-6, 2026 – CME and CEU accredited



THANK YOU!

