NEONATOLOGY TODAY

Peer Reviewed Research, News and Information in Neonatal and Perinatal Medicine

Volume 20 / Issue 2 February 2025

NEONATOLOGY TODAY

ISSN: 1932-7137 (Online), 1932-7129 (Print)
All editions of the Journal and associated manuscripts are available on-line:
www.NeonatologyToday.net
www.Twitter.com/NeoToday

Loma Linda Publishing Company
A Delaware "not for profit" 501(C) 3 Corporation.
c/o Mitchell Goldstein, MD
11175 Campus Street, Suite #11121
Loma Linda, CA 92354
Tel: +1 (302) 313-9984
LomaLindaPublishingCompany@gmail.com

Peer Reviewed

Family Centered Care: Synopsis of Partnering With Parents to Change Measurement and Reporting of Preterm Birth Outcome

Morgan Kowalski

> ***"Rebecca Pearce shares her experience of being unable to find meaningful and reliable information about the outcomes of extremely preterm infants after the birth of her twins at 25 weeks gestation and the loss of one of her daughters."***

This is a synopsis of "Partnering With Parents to Change Measurement and Reporting of Preterm Birth Outcomes" written by Rebecca Pearce, Anne Synnes, MDCM, MHSc, Mei Mei Lam, MD, Lindsay L. Richter, MSc, Fabiana Bacchini, Melissa Jones, Thuy Mai Luu, MDCM, MS, and Annie Janvier, MD, PhD on behalf of the PARENTS' VOICE NETWORK

Rebecca Pearce shares her experience of being unable to find meaningful and reliable information about the outcomes of extremely preterm infants after the birth of her twins at 25 weeks gestation and the loss of one of her daughters. As a NICU parent of a 25-weeker myself, I can attest that Rebecca's struggle to find relevant and accessible information on this subject felt impossible at the time of my son's birth, exacerbating an already traumatic and complicated parenting experience.

Healthcare professionals and researchers traditionally determine information collected during neonatal follow-up visits, considering feasibility, viability, availability, and cost but without considering what information is meaningful to parents. To address this gap in care, CNFUN (Canadian Neonatal Follow-Up Network) set out to identify and measure outcomes that parents identified as important.

CNFUN secured funding for this work from the Canadian Institutes for Health Research strategy for patient-oriented research. The main principles are that patients are meaningful partners throughout the research continuum, the research aims to improve patient outcomes, improve healthcare systems and practices, and involve a multidisciplinary team. Alongside CPBF (Canadian Premature Babies Foundation), CNFUN developed the Parent-Centered Evidence-Based Care for Premature Graduates study, or Parents' Voice study, to capture the voices of a large number of diverse parents, examine the perspectives of parents in more detail, and address potential biases by involving parents in all aspects of the research.

"CNFUN secured funding for this work from the Canadian Institutes for Health Research strategy for patient-oriented research. The main principles are that patients are meaningful partners throughout the research continuum, the research aims to improve patient outcomes, improve healthcare systems and practices, and involve a multidisciplinary team. Alongside CPBF (Canadian Premature Babies Foundation), CNFUN developed the Parent-Centered Evidence-Based Care for Premature Graduates study, or Parents' Voice study, to capture the voices of a large number of diverse parents, examine the perspectives of parents in more detail, and address potential biases by involving parents in all aspects of the research. "

In their first study, CNFUN and CPBF engaged over 1,000 parents of children born before 29 weeks gestation, finding that parents often viewed their child as less impaired than follow-up clinic staff. Perceptions of severity were also studied, with parents feeling that the need for a cochlear implant was less severe. At the same time, cerebral palsy or a language delay diagnosis was viewed as more severe. In subsequent studies, it was found that parents value functionality over diagnosis and prioritize information about how their child is feeding, sleeping, behaving, and breathing over information about neurodevelopment. Additionally, parents expressed a desire for more practical advice around caring for their child, optimism, and a more balanced perspective from healthcare professionals.

Once Parents' Voice study results were shared with parents, clinicians, and researchers involved in the study, seven areas of actionable consensus statements for prematurity follow-up were identified as (1) child well-being, (2) quality of life or function, (3) socioemotional and behavior outcomes, (4) respiratory, (5) feeding, (6) sleeping, and (7) caregiver well-being and mental health. Once these parent-identified domains were agreed on and validated in a workshop consisting of parents, clinicians, and researchers, questionnaires and tools for each area of importance were recommended and published in a scoping review for measuring family, parent, and patient outcomes.

The impact of this collaborative effort was more significant than the identification and recommended measurement of parent-identified areas of importance in follow-up clinics: changes in language around states of health were made to eliminate judgment. For example, healthcare professionals say "severe hearing impairment" instead of "use of hearing aids or cochlear implants." Additionally, parents involved in the study, including Rebecca Pearce and Fabiana Bacchini, were identified as significant contributors to knowledge dissemination across many audiences, including obstetricians, neonatologists and pediatricians, ethicists, and families, with lived experience adding meaning to the information being shared. Success and meaningful change were reached by respectful and total collaboration between parents and healthcare professionals.

"Additionally, parents involved in the study, including Rebecca Pearce and Fabiana Bacchini, were identified as significant contributors to knowledge dissemination across many audiences, including obstetricians, neonatologists and pediatricians, ethicists, and families, with lived experience adding meaning to the information being shared. Success and meaningful change were reached by respectful and total collaboration between parents and healthcare professionals."

This research is significant to me because of my own lived experience in the NICU follow-up clinic with an extremely preterm infant. I remember feeling defensive of my son as he was evaluated and subsequently fell short of age-appropriate neurodevelopmental milestones. I wished we could have also discussed how he overcame the odds by surviving, eating by mouth, and breathing independently. In the future, I would love to see similar studies conducted for parents of infants with varying diagnoses and gestational ages because they, too, deserve to receive information they care about.

Resources:

1. Neurodevelopmental Impairment: Who Defines It? By Annie Janvier, MD, PhD, FRPC
2. Outcomes of Children Born Extremely Preterm: Why Parents' Voices Project is Important
3. Preemie Chat
4. Parent Voices and Evidence-Based Neonatal

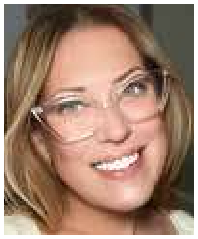
Care: Where we’ve been and where we need to go Video by CHILD-BRIGHT Network

5. Parental and Medical Classification of Neurodevelopment in Children Born Preterm

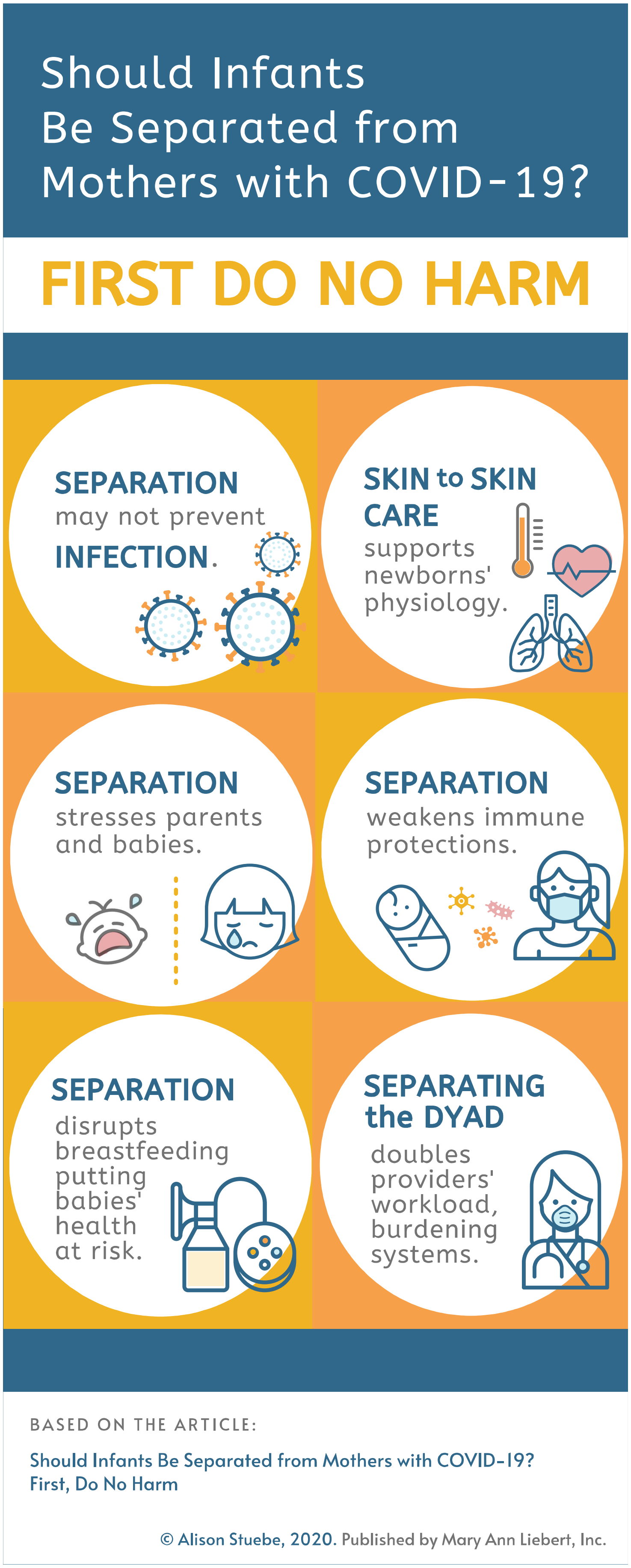
Disclosure: *This work is supported by an educational grant from Chiesi Inc. USA and a Seed 1 Partnership Award from Stanford Impact Labs.*

NT

Corresponding Author



Morgan Kowalski
Program Manager
Family Partner
Golisano Children's Hospital NICU
University of Rochester Medical Center



Should Infants Be Separated from Mothers with COVID-19?

FIRST DO NO HARM

SEPARATION may not prevent **INFECTION.**

SKIN to SKIN CARE supports newborns' physiology.

SEPARATION stresses parents and babies.

SEPARATION weakens immune protections.

SEPARATION disrupts breastfeeding putting babies' health at risk.

SEPARATING the DYAD doubles providers' workload, burdening systems.

BASED ON THE ARTICLE:

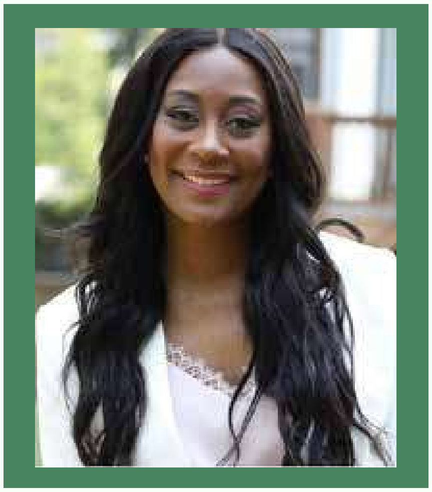
Should Infants Be Separated from Mothers with COVID-19? First, Do No Harm

FCC TASKFORCE WEBINAR

March 13th, 2025

11am-12:30pm PT

Cultivating Compassion: Enhancing NICU Family Experiences & Addressing Bias in Healthcare



Jess Daigle, MD, FAAP
(she/her)

Pediatrician
Founder of Mom & Me MD

Self-Actualization: Live Highest Potential as Parents

COL. Erick Ridout, USA, MC (Ret)
(he/him)

Inventor of POKE
Attending Neonatologist,
Southern Utah and Honolulu, Hawaii

Join for Free
to Register

FCC Taskforce
Program Overview

Generously Supported By:

MeadJohnson NUTRITION

FAMILY-CENTERED CARE
TASKFORCE