

FCC Taskforce Webinar

JANUARY 9TH, 2025

11AM - 12:30PM PT

“Optimizing Organization Mindset to Support Skin-to-Skin and Evidence-Based Neuroprotective Care”



ELIZABETH ROGERS, MD
(SHE/HER)

Professor of Pediatrics, Chief Experience Officer, &
Associate Vice Chair of Faculty Development
UCSF Department of Pediatrics & Division of Neonatology

“The ABC’s of Empathy, Hope, and Clear Communication for NICU Parents”



TERRI L. MAJOR-KINCAIDE, MD, MPH, FAAP
(SHE/HER)

Associate Professor of Pediatrics, Division of Neonatology
Medical Director of Pediatric Palliative Care,
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All-In Meeting

- Break down the hierarchy
- Integrate patient-families
- Prioritize funds to support patient-families
- Intentionally elevate the voices of women, diverse groups, and individuals with rare or unique experiences
- Make it relevant and personal
- Provide support to disabled individuals during in-person meetings
- Invest in building relationships
- Support and include breastfeeding mothers/parents
- Demonstrate the impact, progress, and opportunities
- Capitalize on the expertise in the room
- Remain receptive and responsive to constructive criticism



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Webinar Etiquette

Thank you for helping us make FCC Taskforce Webinars a safe & brave space for all!

By participating, you are agreeing to the following guidelines:

1. Please mute your microphone when you aren't speaking
2. Please turn off your camera if multitasking
3. All questions & comments spoken and written in the chat should be respectful, non-discriminatory, and non-judgmental

Topics discussed may illicit strong emotions and feelings. Please reach out to us if you need support.



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Jessica Fry, MD



Vargabi Ghei, MD



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Henry Lee, MD



Lily Lou, MD, FAAP



Kerri Machut, MD



**Nicole Nyberg,
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Tim Palmer, MD



Jochen Profit, MD



Dharshi Sivakumar, MD



Vincent Smith, MD, MPH



Bob White, MD



Emily Whitesel, MD

Welcome Jessi!



Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW
NICU Parent and NICU Nursing Professional
Development Practitioner



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(Equity, Diversity, Inclusion, & Belonging)

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**Jessi Barnes, MSN, RN, RNC-NIC,
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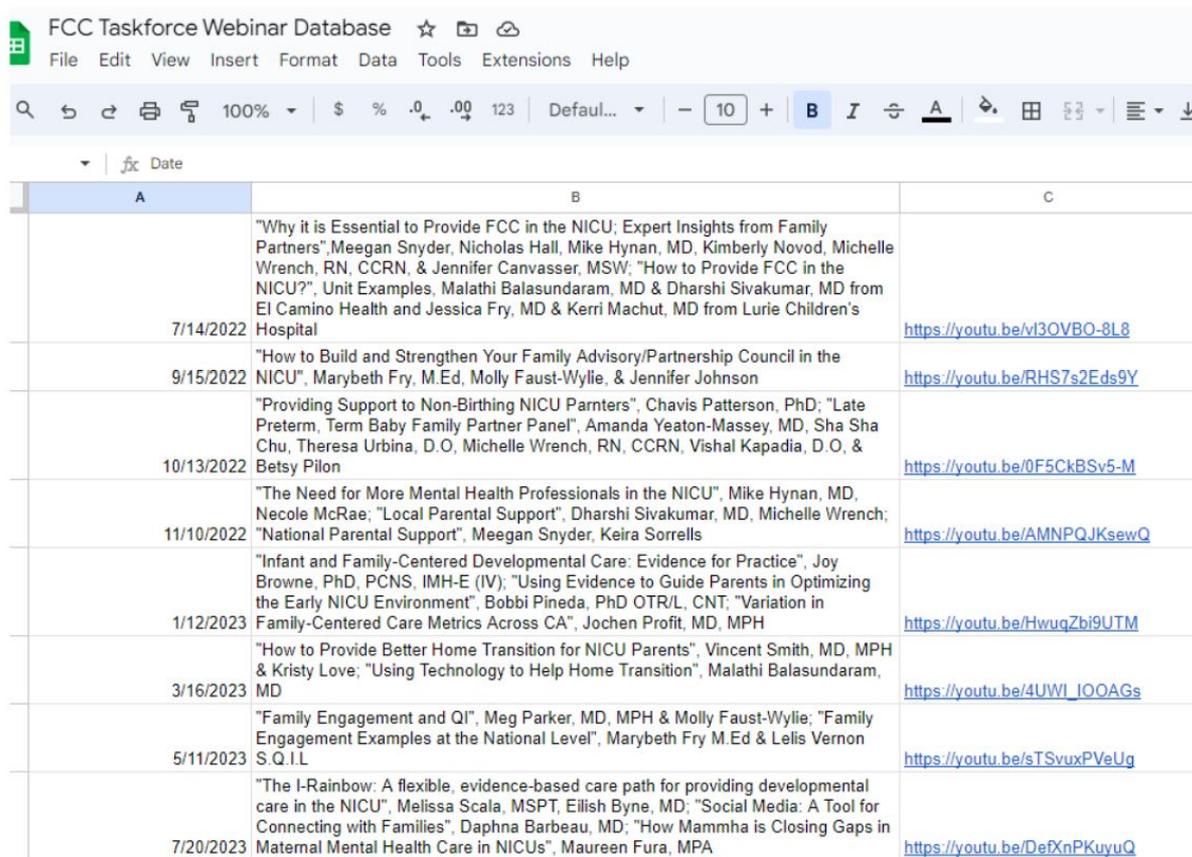
Mia Malcolm, BS, Pharm D.



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Database of Webinar Recordings & Topics



A	B	C
7/14/2022	"Why it is Essential to Provide FCC in the NICU; Expert Insights from Family Partners", Meegan Snyder, Nicholas Hall, Mike Hynan, MD, Kimberly Novod, Michelle Wrench, RN, CCRN, & Jennifer Convasser, MSW; "How to Provide FCC in the NICU?", Unit Examples, Malathi Balasundaram, MD & Dharshi Sivakumar, MD from El Camino Health and Jessica Fry, MD & Kerri Machut, MD from Lurie Children's Hospital	https://youtu.be/vI3OVBO-8L8
9/15/2022	"How to Build and Strengthen Your Family Advisory/Partnership Council in the NICU", Marybeth Fry, M.Ed, Molly Faust-Wylie, & Jennifer Johnson	https://youtu.be/RHS7s2Eds9Y
10/13/2022	"Providing Support to Non-Birthing NICU Parnters", Chavis Patterson, PhD; "Late Preterm, Term Baby Family Partner Panel", Amanda Yeaton-Massey, MD, Sha Sha Chu, Theresa Urbina, D.O, Michelle Wrench, RN, CCRN, Vishal Kapadia, D.O, & Betsy Pilon	https://youtu.be/0F5CkBSv5-M
11/10/2022	"The Need for More Mental Health Professionals in the NICU", Mike Hynan, MD, Necole McRae; "Local Parental Support", Dharshi Sivakumar, MD, Michelle Wrench; "National Parental Support", Meegan Snyder, Keira Sorrells	https://youtu.be/AMNPQJKsewQ
1/12/2023	"Infant and Family-Centered Developmental Care: Evidence for Practice", Joy Browne, PhD, PCNS, IMH-E (IV); "Using Evidence to Guide Parents in Optimizing the Early NICU Environment", Bobbi Pineda, PhD OTR/L, CNT; "Variation in Family-Centered Care Metrics Across CA", Jochen Proffit, MD, MPH	https://youtu.be/HwuqZbi9UTM
3/16/2023	"How to Provide Better Home Transition for NICU Parents", Vincent Smith, MD, MPH & Kristy Love; "Using Technology to Help Home Transition", Malathi Balasundaram, MD	https://youtu.be/4UWI_JOOAGs
5/11/2023	"Family Engagement and QI", Meg Parker, MD, MPH & Molly Faust-Wylie; "Family Engagement Examples at the National Level", Marybeth Fry M.Ed & Lelis Vernon S.Q.I.L	https://youtu.be/sTSvuxPVeUg
7/20/2023	"The I-Rainbow: A flexible, evidence-based care path for providing developmental care in the NICU", Melissa Scala, MSPT, Eilish Byne, MD; "Social Media: A Tool for Connecting with Families", Daphna Barbeau, MD; "How Mamma is Closing Gaps in Maternal Mental Health Care in NICUs", Maureen Fura, MPA	https://youtu.be/DefXnPKuyUQ



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January Poll

Help us understand your unit's practices around mental health screenings for NICU families!

Does your unit screen NICU families for perinatal mood and anxiety disorders?
(ex. PMAD Ex Edinburgh Scale)



**All poll responses
can be found here!**



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2024 FCC NICU Measures REDCap Survey & Benchmarking

- Collaborated with Family Partners to **create NICU FCC Measures in seven categories**
- Created **comprehensive REDCap survey** to be completed by clinicians and their teams
- **NICU FCC Measures Survey**
 1. NICU Framework/Infrastructure (9)
 2. Family Support (19)
 3. Family Integration into Care (16)
 4. Family Integration into QI & Processes (1)
 5. NICU Environment (7)
 6. Staff Education (2)
 7. Balancing Measures (4)

Why should your unit participate?

- Immediate unit performance score upon survey completion
- Benchmark unit performance with participating NICUs (all identifying data kept anonymous) at end of study
- Collaborate with participating NICUs on topic-specific QI work

Please reach out to receive our survey!

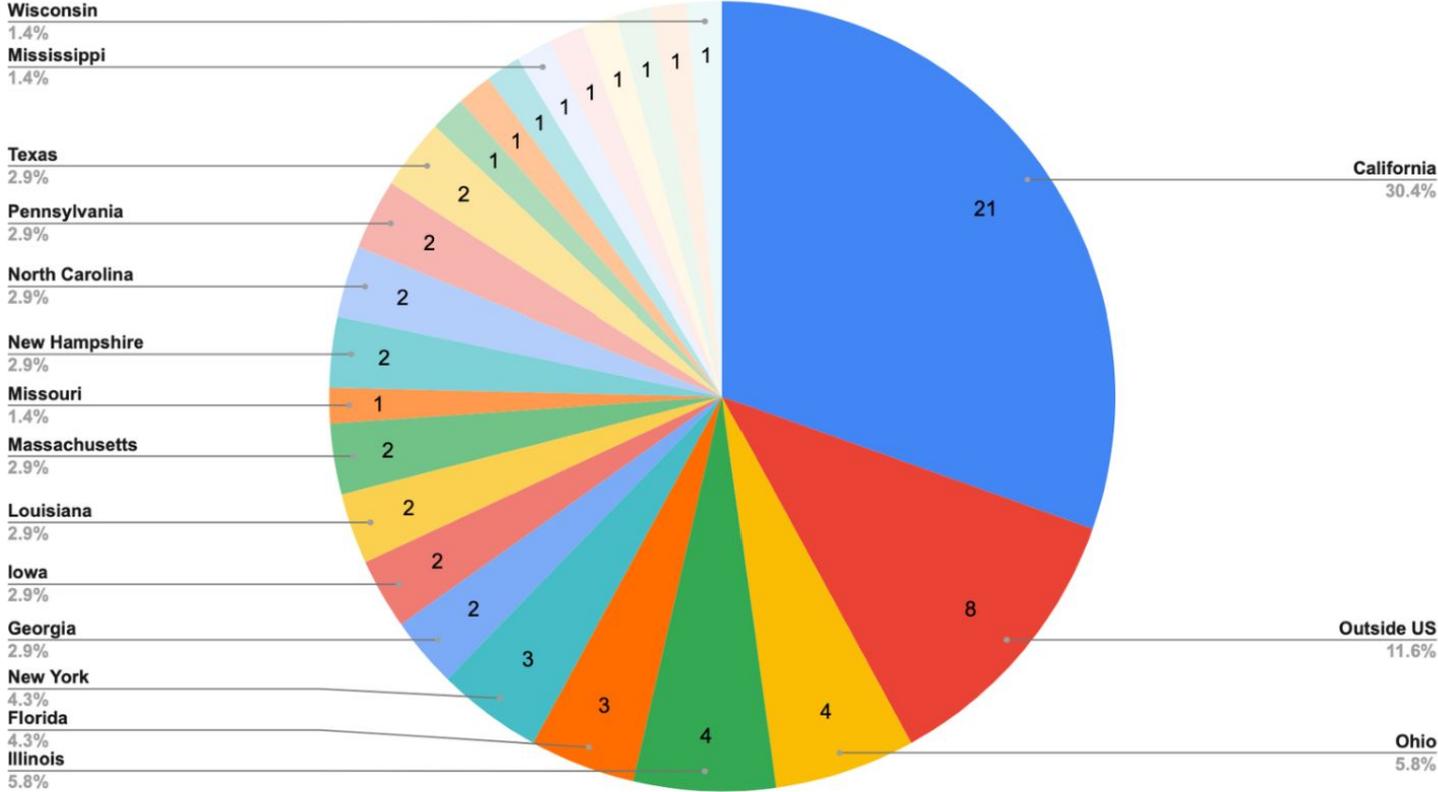


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NICU FCC Measures Survey Participants

Count of US States



Participating Centers

Akron Children's NICU at Cleveland Clinic Akron General
Ann & Robert H. Lurie Children's of Chicago
Beacon Children's Hospital Neonatal Intensive Care Unit
Beth Israel Deaconess Medical Center
Bharati Hospital and Research Center
Boston Medical Center
Bronson Children's Hospital
Centre Hospitalier Universitaire Saint-Pierre
Children's Hospital Colorado
Children's Hospital new Orleans
Children's Hospital of The King's Daughters Neonatal Intensive Care Unit
Children's Mercy
CHU Sainte-Justine
Cincinnati Children's Hospital Medical Center
Cottage Health NICU
Department of Intensive Care and Congenital Malformations of the Newborn and Infant
El Camino Health
Elliot Hospital NICU
Good Samaritan Hospital
Grady Memorial Hospital
HCA Northwest
HCA University Hospital`
Ilmatar
Joe DiMaggio Children's Hospital Wasie Neonatal ICU
John Muir Medical Center
Kaiser Rosville
Kaiser South Bay NICU
Lenox Hill Hospital
Loma Linda University
Maynard Children's Hospital NICU at East Carolina University Health
Medical University of South Carolina Shawn Jenkins Children's Hospital
MemorialCare Miller Children's & Women's Hospital
Mercy Medical Center
Monroe Carell Jr. Children's Hospital at Vanderbilt
Mount Sinai
Multicare Deaconess NICU

Natividad NICU level 3
Neonatal Critical Care Unit
Neonatal Intensive Care Unit and Family Suites
North Mississippi Medical Center
Northwestern Medicine - Prentice Women's Hospital
Penn Medicine Chester county
Penn State Hershey Children's Hospital
Providence Santa Rosa Memorial Hospital
Rady Children's Hospital-San Diego
Rady Children's NICU at Rancho Springs Medical Center
Rainbow Babies and Children's Hospital
San Joaquin General Hospital Intensive Care Nursery
Santa Clara Valley Medical Center
Sidra Medicine
Tel Aviv Medical Center NICU
Tift Regional Medical Center
Touro Infirmary
UC Davis
UNC Heath Newborn Critical Care Center
University Health
University of California San Diego
University of California San Francisco Benioff's Children's Hospital Oakland
University of California, Davis
University of Cincinnati Medical Center
University of Iowa Health Care - Stead Family Children's Hospital - Neonatal Intensive Care Unit
University of Rochester Medical Center
University of Texas Medical Branch
UW Health SwedishAmerican
UWHealth Kids American Family Children's Hospital
Valley Children's Hospital Neonatal Intensive Care Unit
We don't have a name
Wellington Neonatal Intensive Care Unit
Zuckerberg San Francisco General Hospital



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Optimizing Organizational Culture to Provide Neuroprotective Care for Best Outcomes

Elizabeth Rogers, MD
Professor of Pediatrics, UCSF
Director, UCSF ROOTS Program
Associate Vice Chair, Department of Pediatrics



California
Preterm Birth
Initiative



Acknowledgement & Perspective Disclosure

- CPQCC
NEOBrain QI
Collaborative
- VON
All Care is
Brain Care
Collaborative



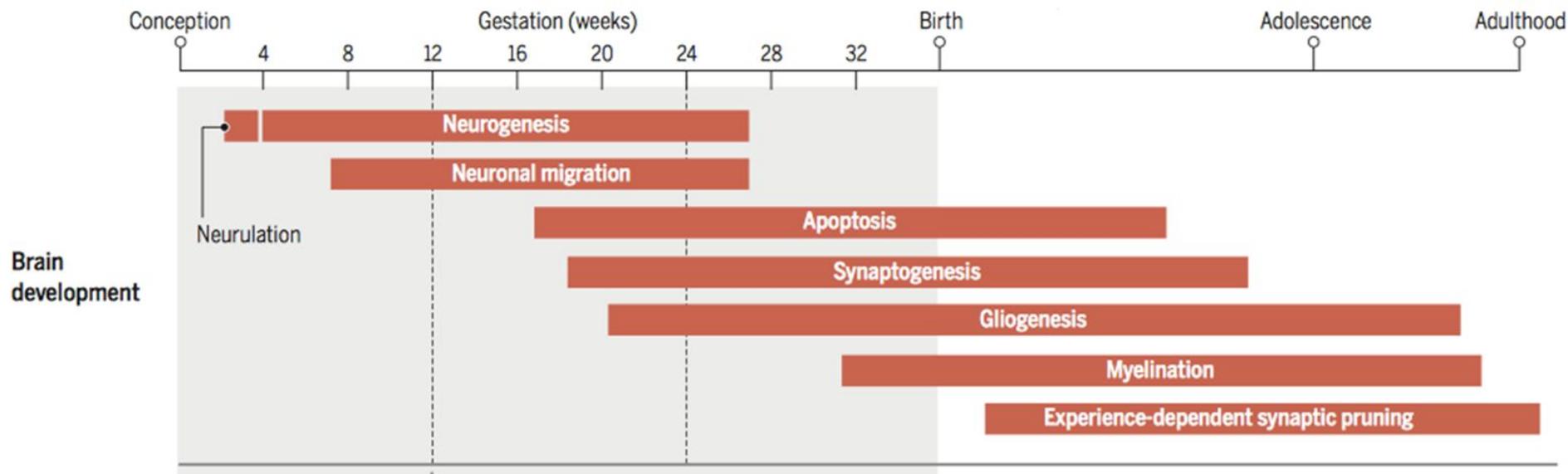
Objectives



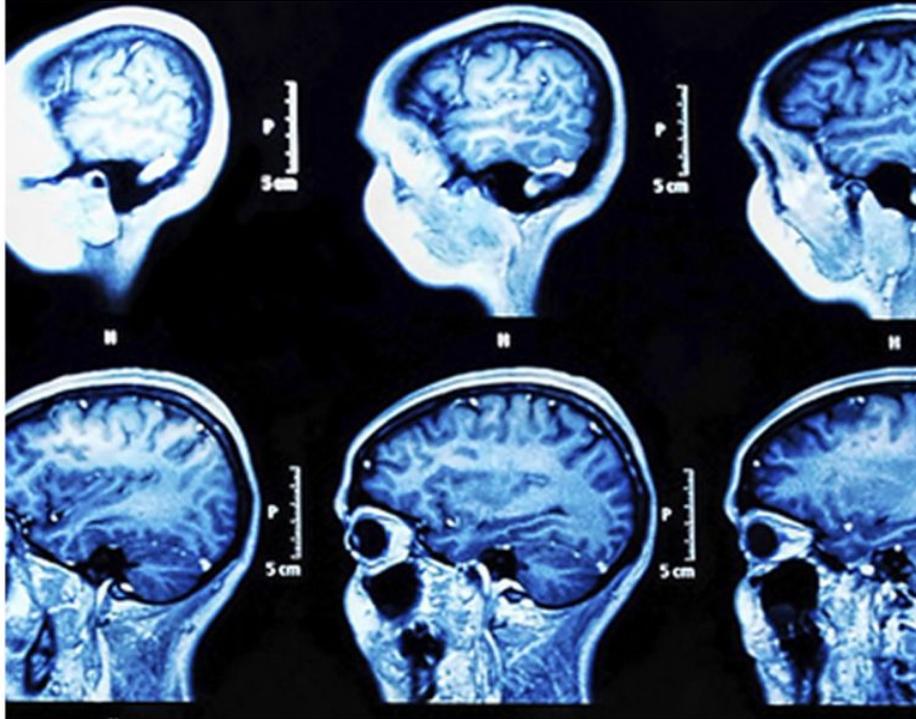
- To understand how creating a *culture* of neuroprotective care may improve outcomes for our patients
- To understand skin to skin care as an important quality target for improvements in both family partnership and neuroprotective care
- To ensure equity, justice, and sustainability are intentionally built into the culture of neonatal neuroprotective care
- To consider *how* we know things and get change implemented







Survive and Thrive



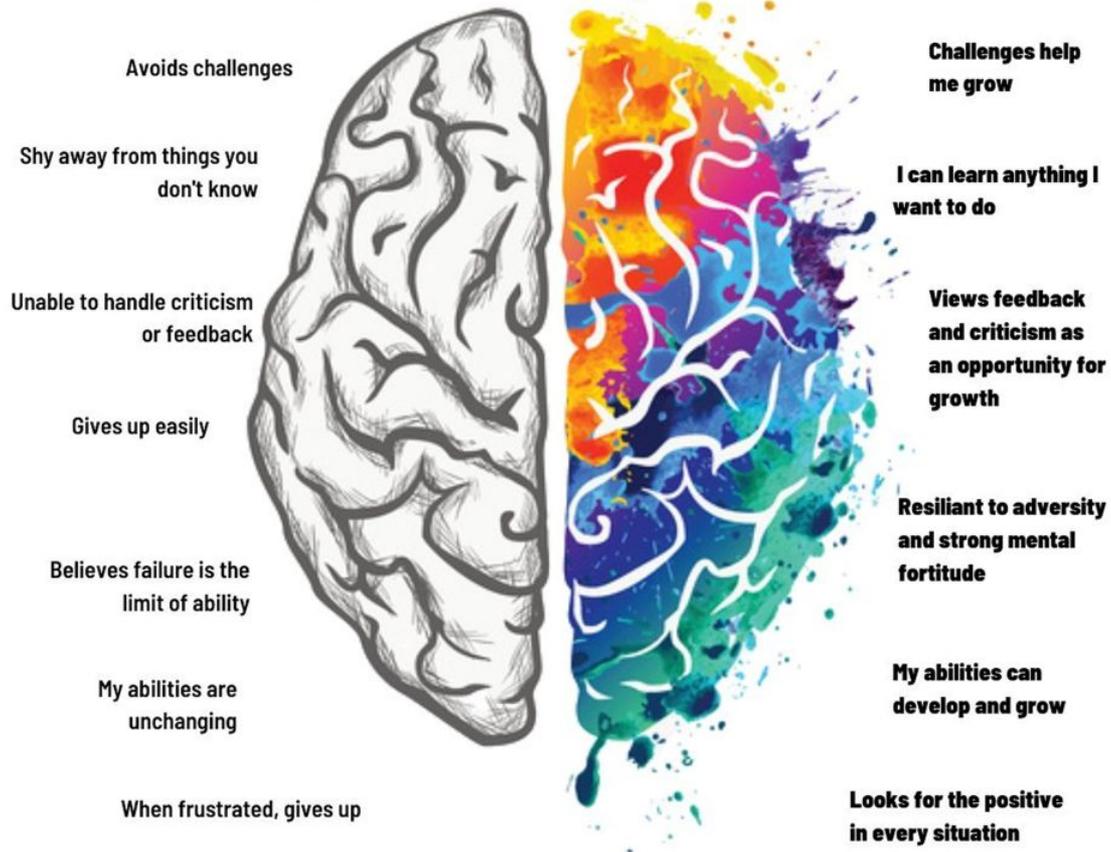
Every interaction with an infant and their family in the neonatal intensive care setting is an opportunity to be brain-focused and have a direct impact on the developing brain.



FIXED MINDSET

VS

GROWTH MINDSET



FIXED MINDSET

VS

GROWTH MINDSET

Avoids challenges

Shy away from things you
don't know

Unable to handle criticism
or feedback

Gives up easily

Believes failure is the
limit of ability

My abilities are
unchanging

When frustrated, gives up



Challenges help
me grow

I can learn anything I
want to do

Views feedback
and criticism as
an opportunity for
growth

Resilient to adversity
and strong mental
fortitude

My abilities can
develop and grow

Looks for the positive
in every situation



"We don't do that here."

"How could we do that here?"

What is Culture?

- **Organizational culture** refers to the shared beliefs, perceptions, and values in an organization
- **“Culture eats strategy for breakfast.”**
- Source unknown



Where does culture come from?

Formal statements of organizational philosophy, charter, creeds

Organizational design and structure, systems and procedures

How leaders allocate rewards, status, resources

What leaders pay attention to, manage, control

Leader reactions to critical incidents and crises

Role modeling, teaching, coaching by leaders

How leaders recruit, select, promote, retire, and excommunicate members

Culture of Care: All Care is Brain Care



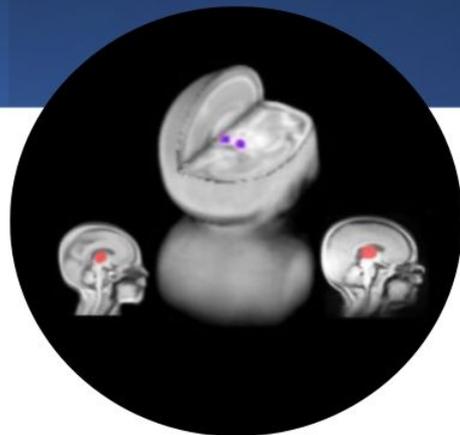
Culture of Care: Families as partners



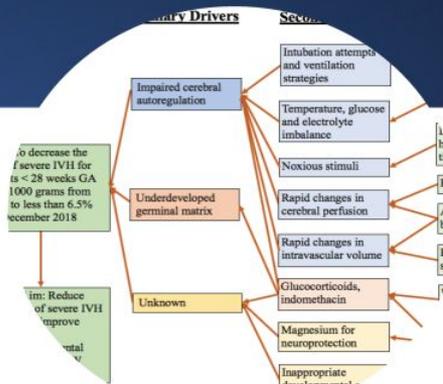
Culture of Care: Caring for Caregivers



Neuroprotective Care to Optimize Brain Health and Outcomes



Protect



Prevent

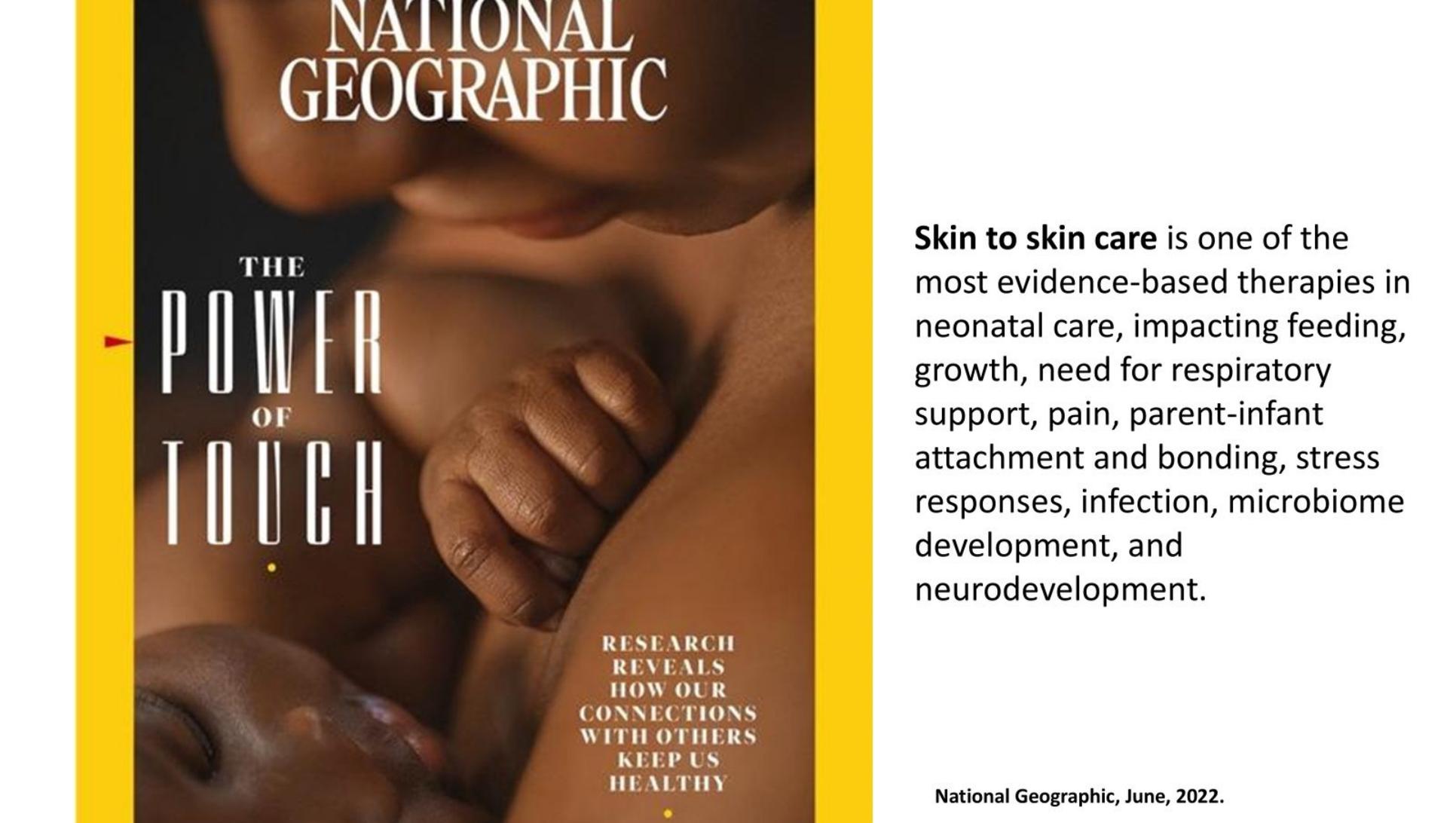


Promote



Prepare



The image is a National Geographic magazine cover. It features a close-up, warm-toned photograph of a person's face and hands. The person's eyes are closed, and their hands are gently touching their face. The background is a soft, golden-brown color. The text is overlaid on the image in white and yellow. At the top, the words 'NATIONAL GEOGRAPHIC' are written in a large, white, serif font. Below that, the title 'THE POWER OF TOUCH' is written in a large, white, sans-serif font, with 'THE' and 'OF' in smaller letters. At the bottom, a short article preview is written in a smaller, white, sans-serif font. The entire cover is framed by a yellow border on the left and right sides.

NATIONAL
GEOGRAPHIC

THE
POWER
OF
TOUCH

RESEARCH
REVEALS
HOW OUR
CONNECTIONS
WITH OTHERS
KEEP US
HEALTHY

Skin to skin care is one of the most evidence-based therapies in neonatal care, impacting feeding, growth, need for respiratory support, pain, parent-infant attachment and bonding, stress responses, infection, microbiome development, and neurodevelopment.

National Geographic, June, 2022.

History of SSC

- Long been employed as a means for providing warmth, to stimulate milk production
- Utilized broadly in the world
- Recognized in the 1970s as a medical intervention, likely because high resource settings had created the incubator
- 1970s → Sweden, Colombia
 - In Colombia, aiming for 20 h/day of KMC with mother or surrogate resulted in 70% reduction in mortality
- 1996 → “KMC” coined by a group working with the World Health Organization



It's beneficial for all infants

- Skin to skin care, contact, or therapy (SSC)
 - Kangaroo care
 - Kangaroo mother care (KMC)
 - Immediate kangaroo mother care (iKMC)
- Decreases the separation time between parent and infant
- In **term** infants, shown to promote breastfeeding and regulates heart and respiratory rate and pattern
- In **preterm** babies, shown to reduce mortality and infection rates, promotes breastfeeding, and leads to better weight gain

ORIGINAL ARTICLE

Immediate “Kangaroo Mother Care” and Survival of Infants with Low Birth Weight

WHO Immediate KMC Study Group*

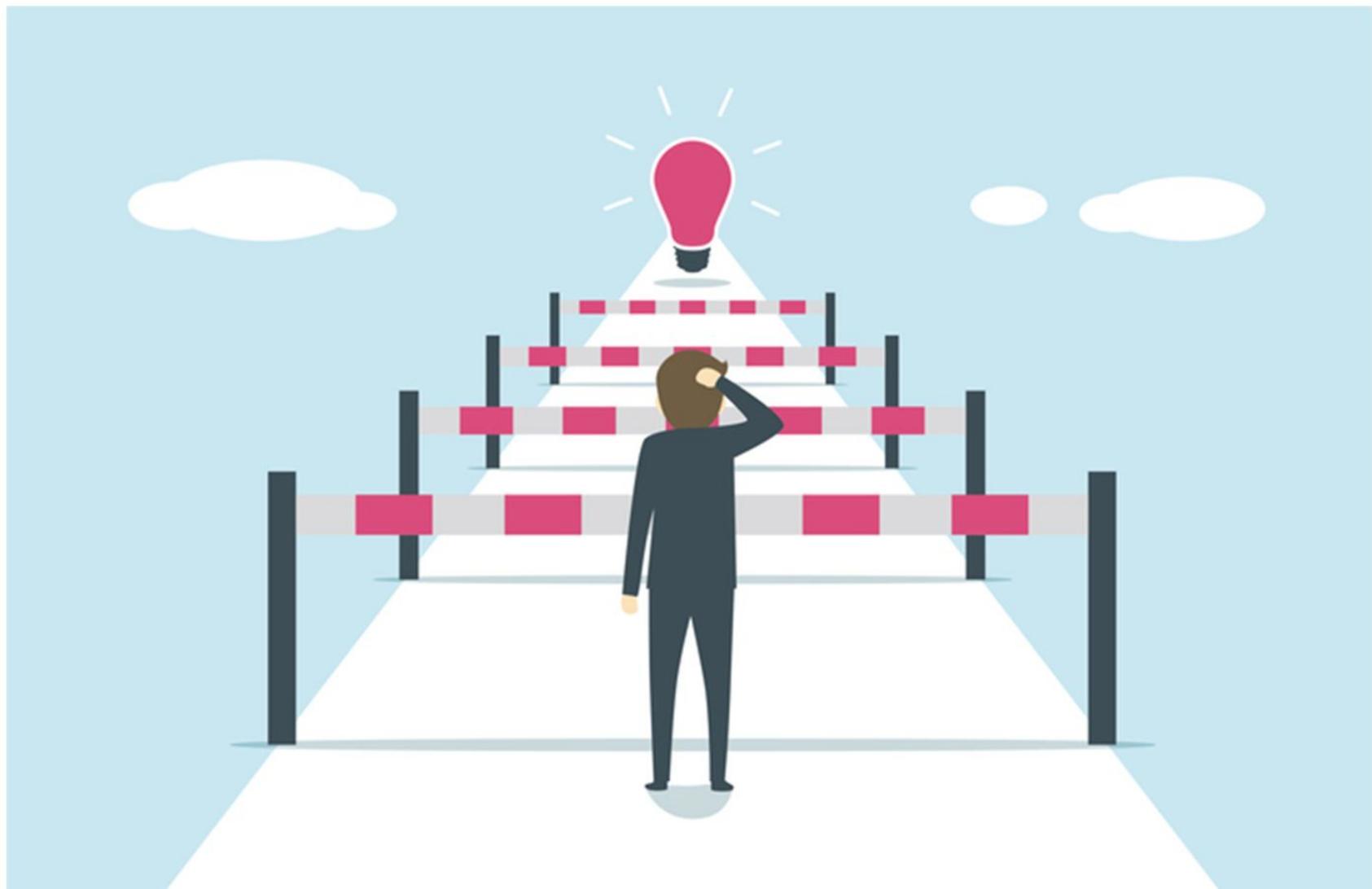
- Multicenter RCT of 3200 infants across 5 hospitals in Ghana, India, Malawi, Nigeria, and Tanzania
- Immediate KMC improved survival by 25% compared with KMC after stabilization
 - 12% vs 15.7%, RR 0.75 (0.64-0.89)
- Lower rates of hypothermia and suspected sepsis
- Higher mean maternal satisfaction scores
- Earlier initiation of breastmilk feeds, earlier full breastmilk feeds
- Results may be dose-dependent
- Appears to be safe

Myth Busting!

Myth – Skin to skin care cannot be performed in a sick or unstable newborn.

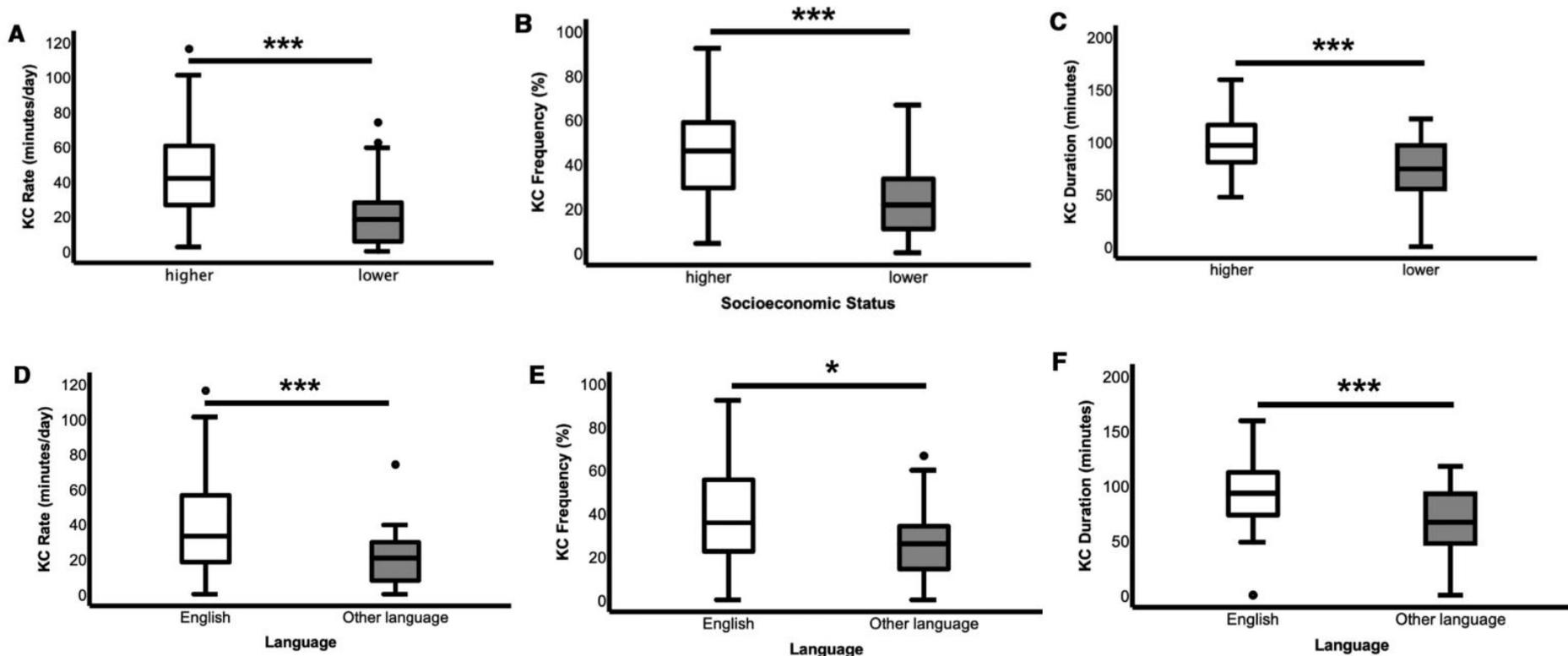
Common Arguments

1. The baby is too sick.
What is too sick? Providers have various definitions. Is it umbilical lines, is it intubated, on HFOV, on vasoactive medications?
2. The parents are too nervous.
3. We cannot maintain neutral head position, or It's not in our IVH bundle.
4. It might lead to unplanned extubation.
5. We don't have enough staff to transfer safely.



Disparities in Kangaroo Care for Premature Infants in the Neonatal Intensive Care Unit

Edith Brignoni-Pérez, PhD,^{*†} Melissa Scala, MD,[‡] Heidi M. Feldman, MD, PhD,^{*}
Virginia A. Marchman, PhD,[§] Katherine E. Travis, PhD^{*}

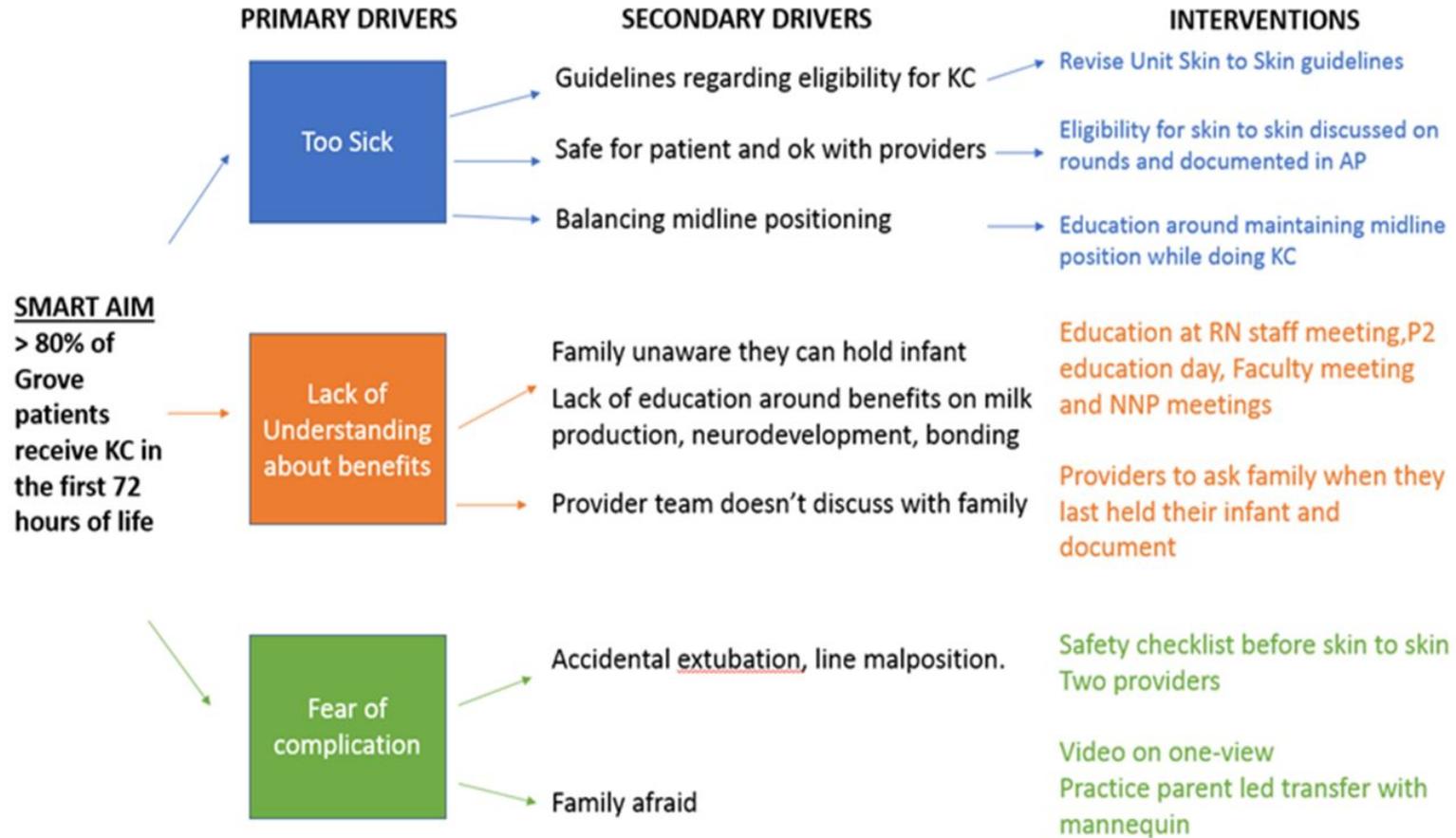


UCSF- Baseline State (2017 edition)

- Neurodevelopmental focus of care for preterm infants since QI implementation “Premie Project” launched end of 2017
- Change in protocol to allow and encourage skin to skin care within 72h for infants <28W
 - Increased SSC from 7% to 84% within 72h from June 2017 to Dec 2019 (Minot et al, Neonatal Network, 2021)
 - Unit-specific protocol
 - Widespread education
 - Infant readiness checklist
 - Decreased IVH from 14% to <1.2% over 2.5 years
- Pandemic – improvement in SSC not sustained



Driver Diagram for Early SSC



Kangaroo Care



in the

Intensive Care Nursery

Why is this important for me and my baby? What is this?

Kangaroo Care will help you:

- ✔ Feel closer to your baby
- ✔ Reduce your stress
- ✔ Make more milk (that protects your baby)
- ✔ Learn how to respond to your baby's needs
- ✔ Have more confidence in your parenting skills

Kangaroo Care will help your baby:

- ✔ Gain weight
- ✔ Maintain a regular heart rate and breathing rate
- ✔ Maintain their body temperature
- ✔ Know you better
- ✔ Have a better chance at breastfeeding
- ✔ Be ready for breastfeeding

✔ Kangaroo care, also called skin to skin, is when you hold your (diapered) baby naked on your bare chest.

✔ Kangaroo care is healing in many ways for both you and your baby.

Who can kangaroo? And how?

- ✔ Moms and dads can both provide Kangaroo care.
- ✔ Your nurse will help you decide when it is safe to hold your baby this way
- ✔ Your baby may appear fragile, but this is the most natural way to help your baby grow and heal. Your nurse will help make the right decision about holding your baby.



Before you kangaroo:

Plan to hold your baby for at least 1 hour (one full sleep cycle)

Use the restroom, pump, get a drink and place items you will need next to you

Wear a button-down or zip-up top, or get a gown from your nurse that opens in the front

Remove your bra so that you have as much skin to skin contact as possible

Discuss with your nurse how you will get your baby to your chest. Talk about whether you and your baby are ready for you to pick up your baby up out of the bed.

Pump again right after holding your baby! The hormones released during kangaroo care help you make more milk.

ENJOY YOUR BABY

Figure A



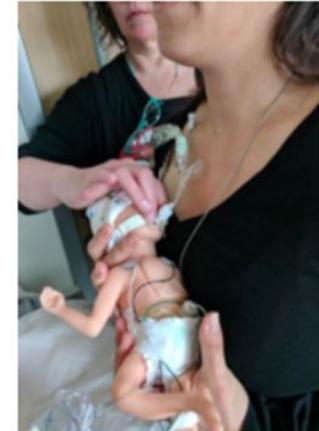
Figure C



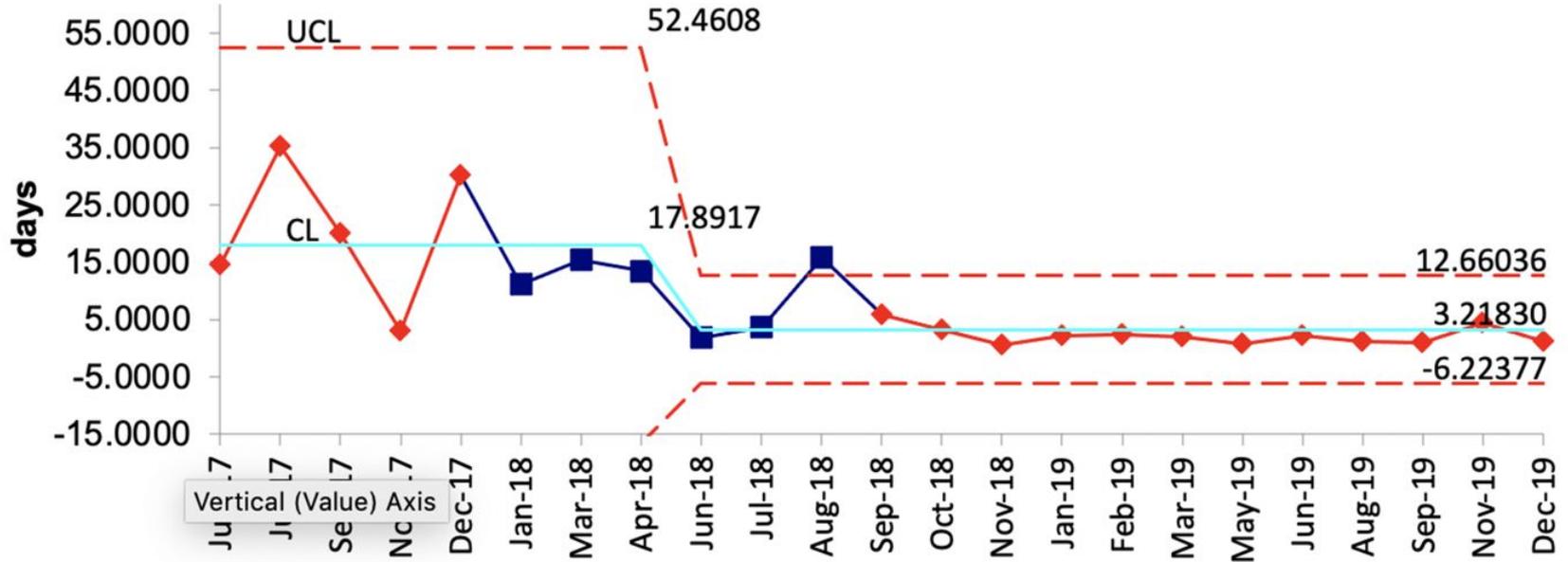
Figure B



Figure D

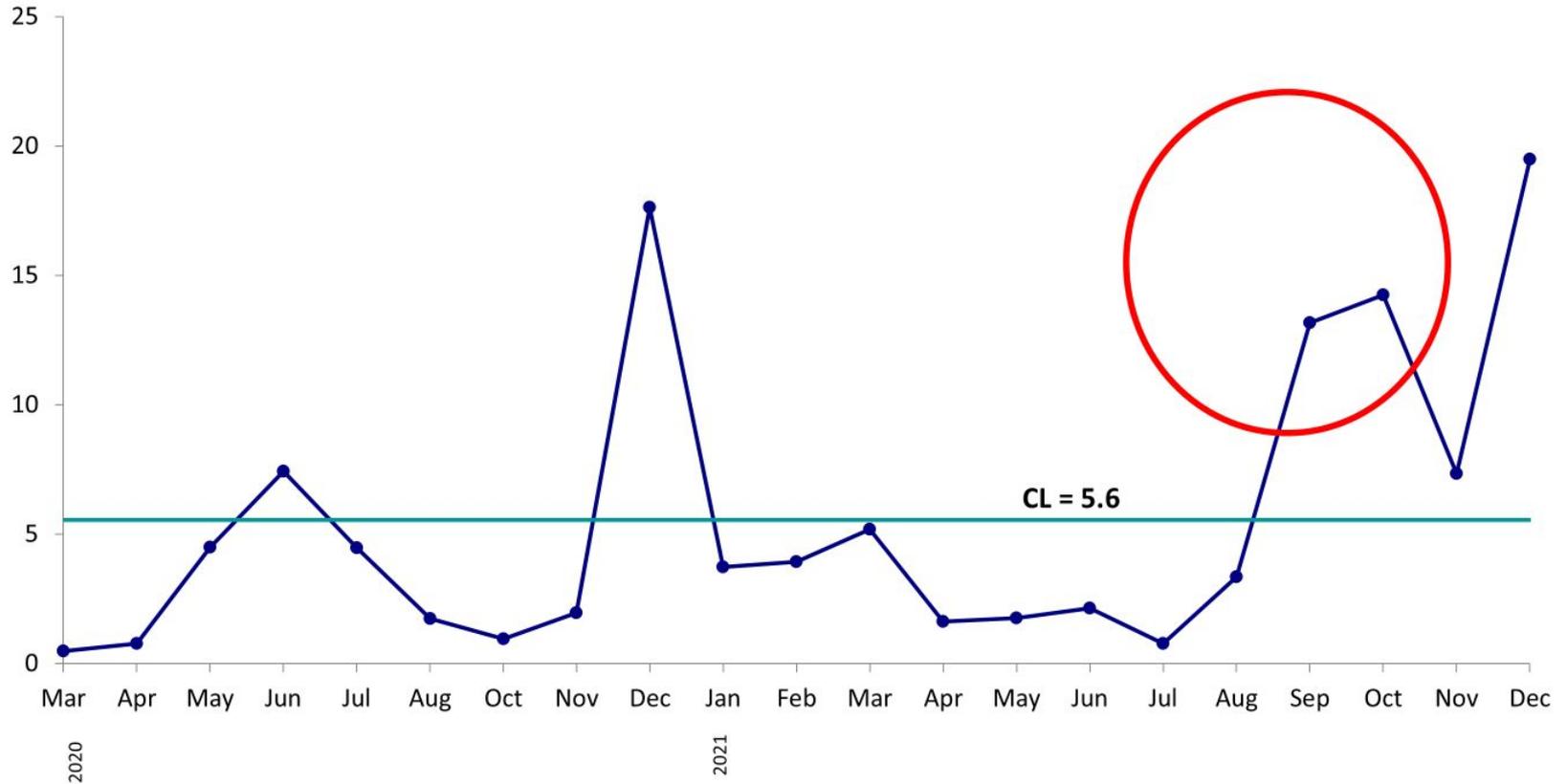


Days to First Hold X Chart



UCSF- Baseline State (2022 edition)

Days to first hold (<28W)- Run Chart





NEOBrain
Collaborative

ICN BCH-SF Multidisciplinary QI Team

Megan Brown, RN

Jeannie Chan, CNS

Rachelle Elul, RN

Tanya Hatfield, RN

Katie Kramer, MD

Tiana Nguyen, OT

Taylor Park, CCLS

Jay Paulasa, RN

Laurel Pershall, NNP

Mary Jo Potts, PT

Elizabeth Rogers, MD

Diana Rogosa,

Parent Liaison

Sam Wynn, RN



Example QI metrics:

- Early skin to skin care (SSC)***
- Family centered rounds***
- 2 person cares/touch times***

Aims

Global Aim: Improve optimal neurodevelopmental care by increase positive touch for all infants <32 weeks, emphasizing parental positive touch

Local SMART AIM: To increase skin to skin for all eligible infants in first week from 71% to > 90% by June 2023

Balancing Measures: Unplanned extubation, severe IVH

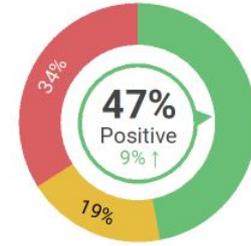
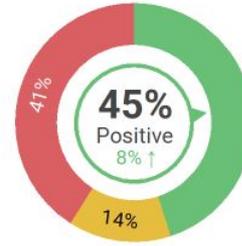
Lessons learned

- Multidisciplinary team was critical to our success
 - PT/OT, parent liaison
- Challenging to reach all families to provide parent handouts and education but critically important
- Data collection time-intensive – need for better documentation and reports through EMR
- All change was facilitated as part of the broader culture change of "All Care is Brain Care"

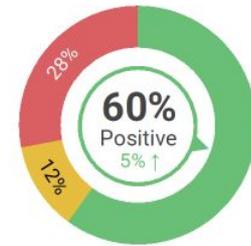


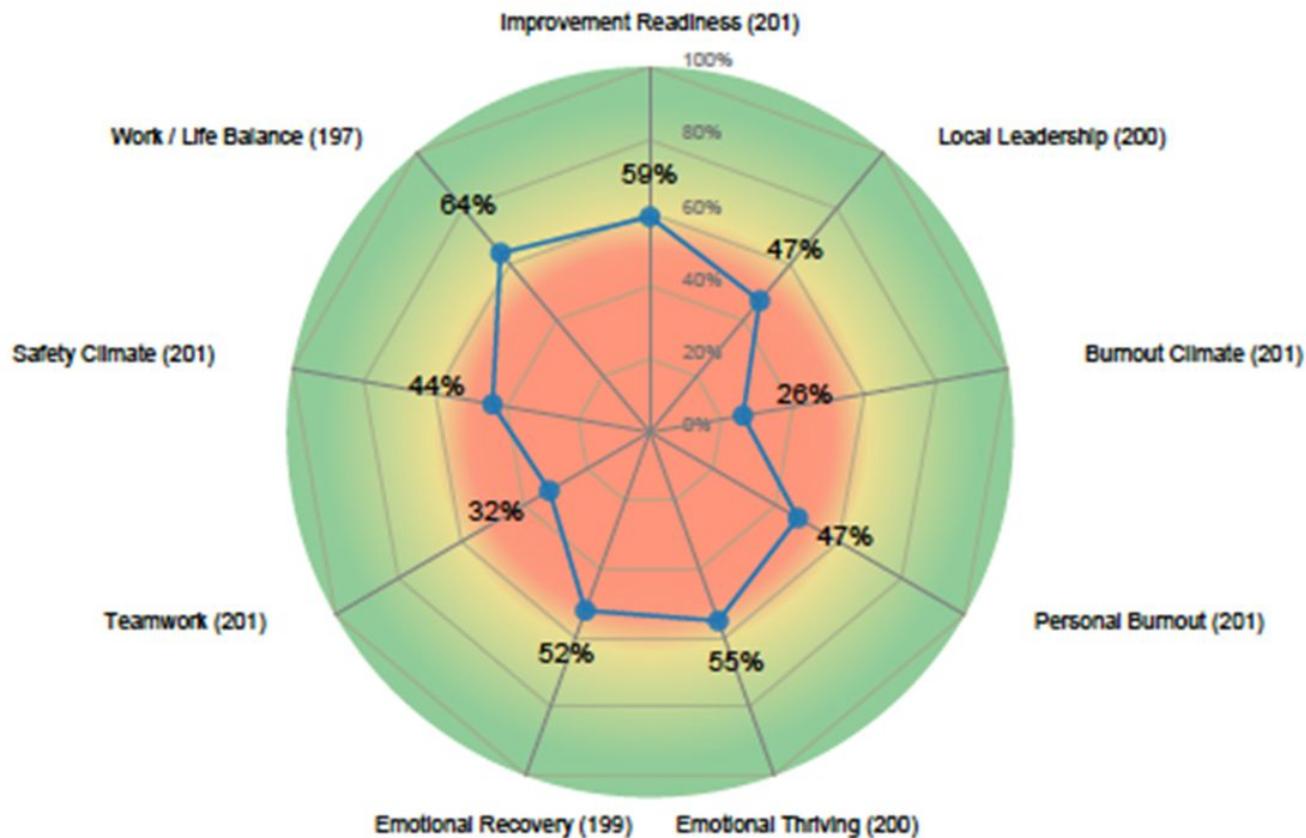


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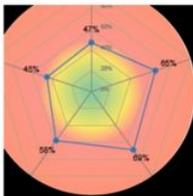


Source Data: Apr 2019

Institution: CPQCC Grow Baby Grow Collaborative

Work Setting(s): UCSF Childrens Hospital

Position(s): All Positions



Responsibility
 Teamwork
 Integrity
 Mindfulness
 Engagement
Professionalism
 Pragmatism
 Reliability
 Dedication
 Conscientiousness
 Accountability

Knowledge
 Learning
 Integrity
Excellence
 Dedication
 Making-a-Difference
 Innovation

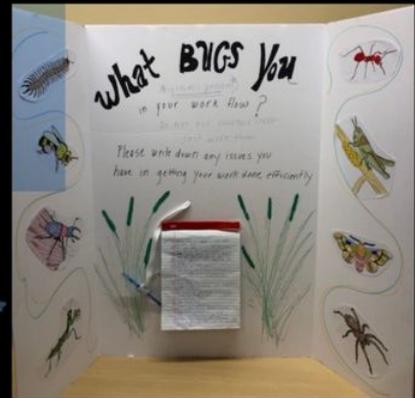
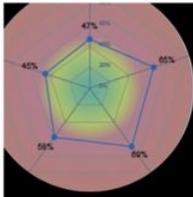
Kindness
 Respect
 Dedication
Compassion
 Making-a-Difference
 Caring
 Empathy

Flexibility
 Resilience
 Humility
Openness
 Mindfulness
 Proactivity
 Versatility

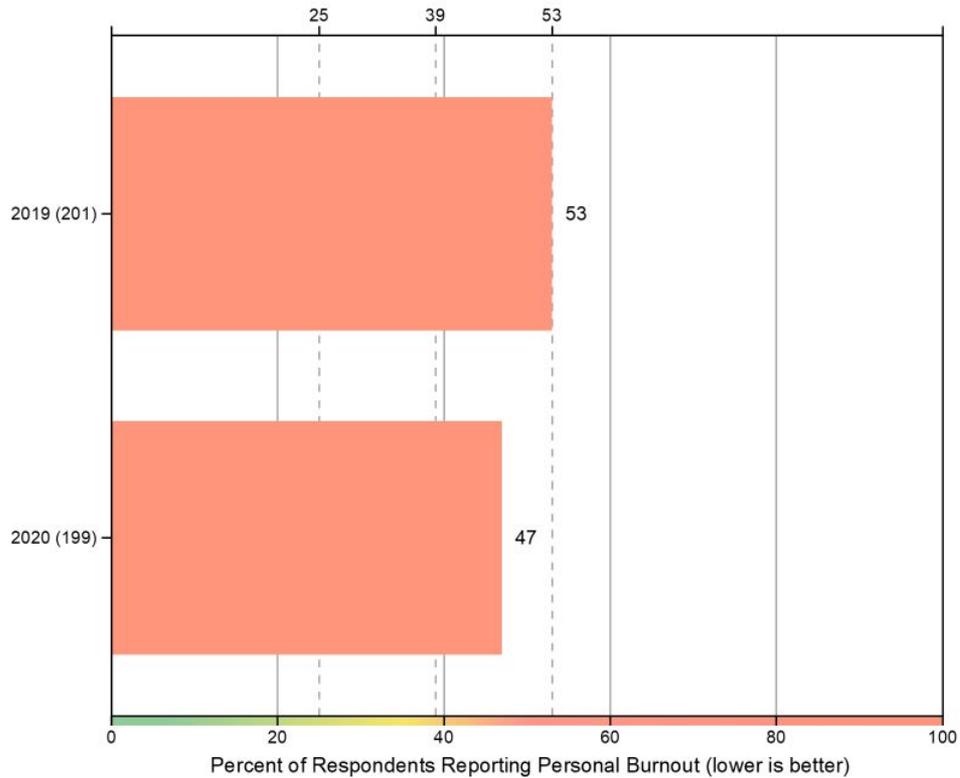
Recognition
 Teamwork
 Reliability
 Positivity
 Humor
Supportiveness
 Happiness
 Honesty
 Respect

Community Groups:

1. Teamwork
2. Communication
3. Leadership
4. Burnout Climate



Personal Burnout Historical Comparison



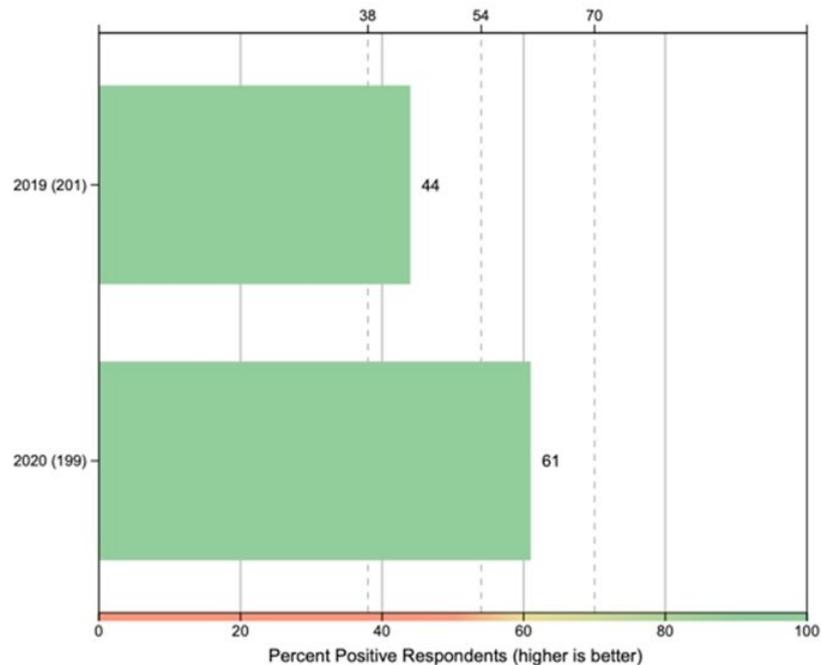
Source Data: April/May 2021

Institution: CPQCC - MA NICU Collaborative

Work Setting(s): UCSF Childrens Hospital

Position(s): All Positions

Safety Climate Historical Comparison



Source Data: April/May 2021

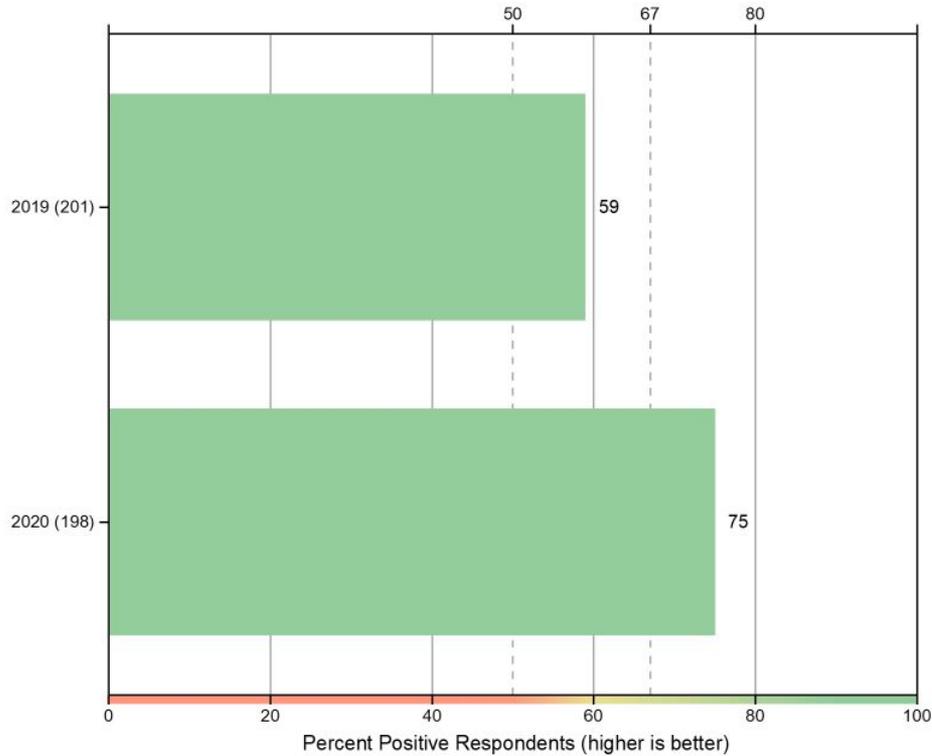
Institution: CPQCC - MA NICU Collaborative

Work Setting(s): UCSF Childrens Hospital

Position(s): All Positions



Improvement Readiness Historical Comparison



Benchmarks: 2020 Q3 US Hosp.
25th: 50% 50th: 67% 75th: 80%
Percent Positive Percentile(s)
n = 319950 responses
From 13544 units/departments

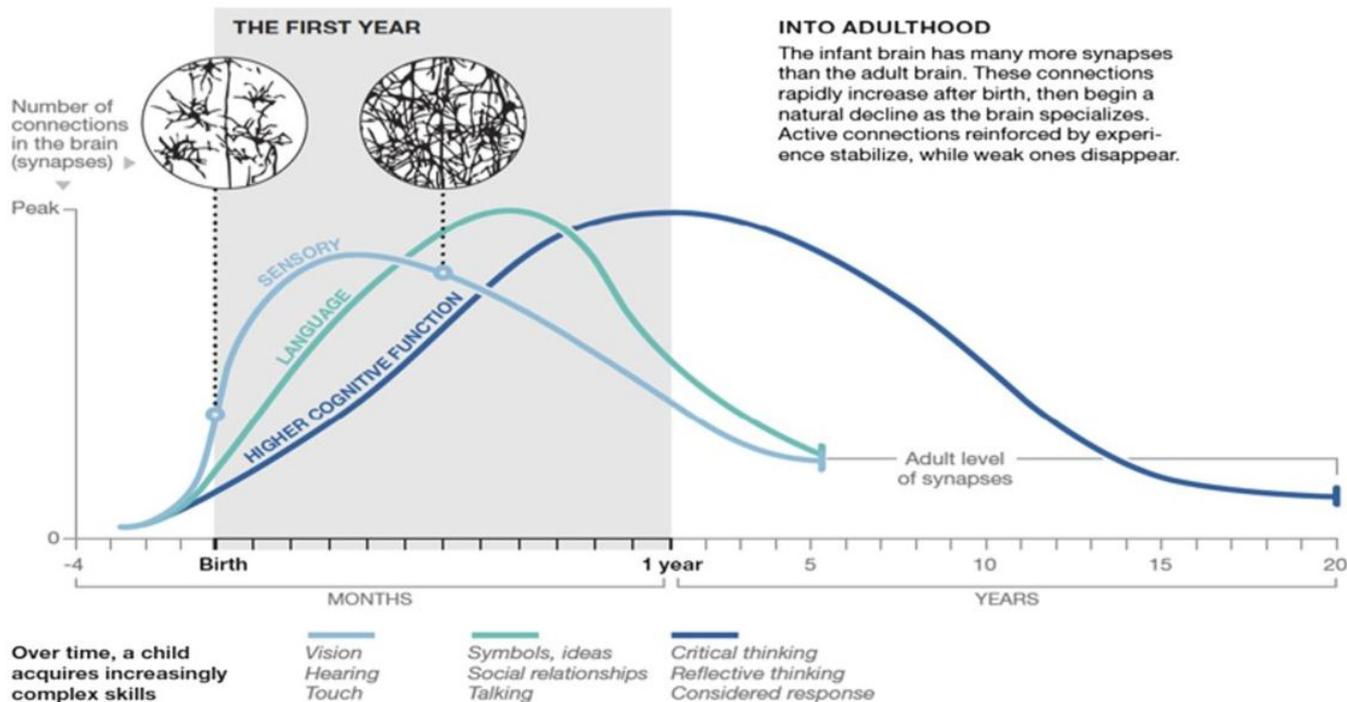
Source Data: April/May 2021
Institution: CPQCC - MA NICU Collaborative
Work Setting(s): UCSF Childrens Hospital
Position(s): All Positions

Culture of Care: Families as partners



THE NEURAL NETWORK

The brain begins developing in the womb and achieves dramatic levels of growth during the first few years of life. During this time positive experiences contribute to building a strong brain architecture.



GRAPHIC: LAWSON PARKER, NGM STAFF. SOURCE: CHARLES NELSON, HARVARD MEDICAL SCHOOL; PAT LEVITT, CHILDREN'S HOSPITAL LOS ANGELES
SYNAPSE DRAWINGS BASED ON GOLGI STAIN PREPARATIONS FROM CONEL (1939-1967)

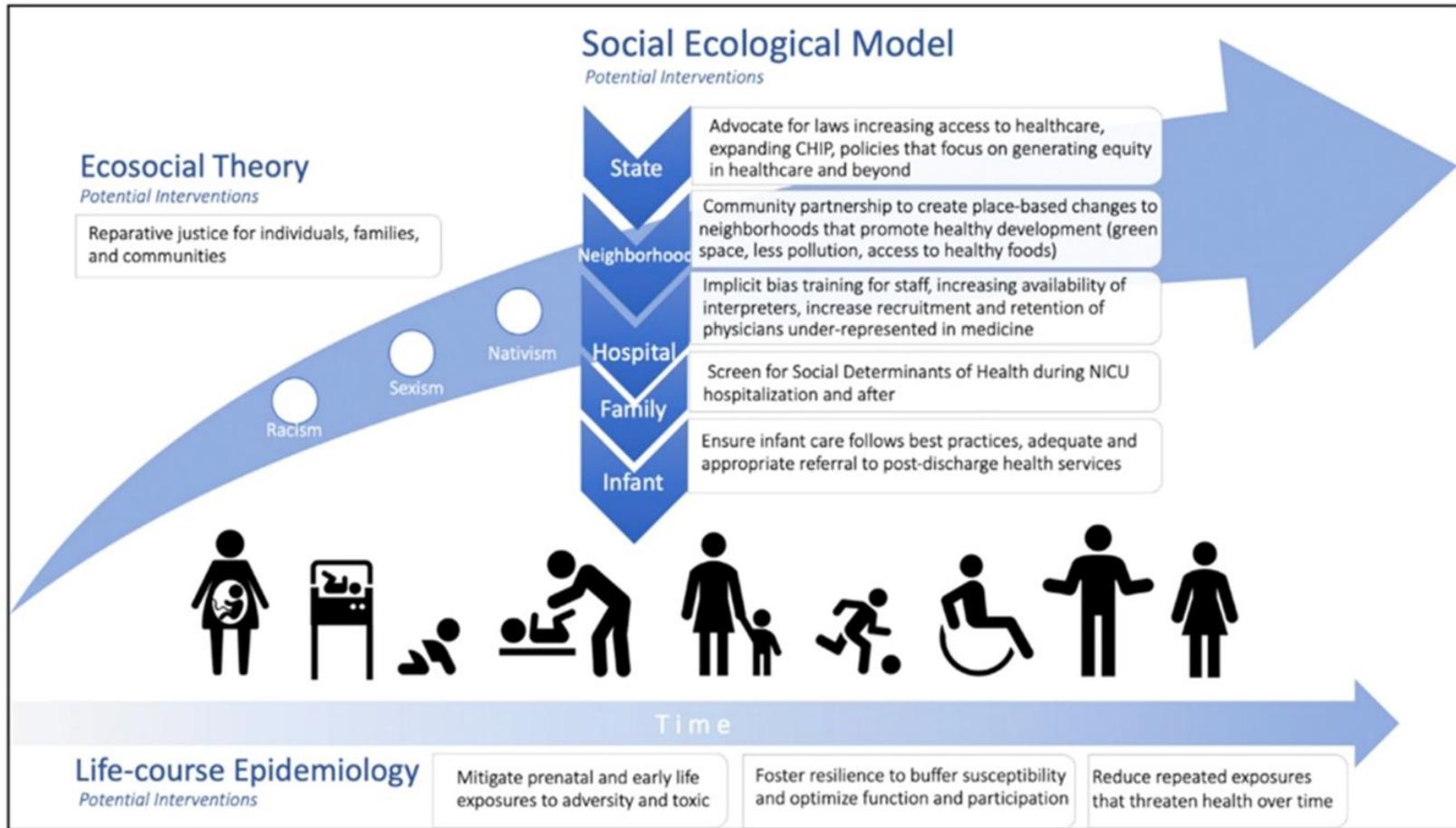


Fig. 1 – Using epidemiologic theory to identify drivers of inequities in long-term outcomes of preterm infants and develop strategies to reduce their impact over time.



IMMEDIATE KANGAROO CARE (IKMC) TO IMPROVE SURVIVAL OF LOW BIRTH WEIGHT INFANTS

*A Town Hall of International Experts hosted by the American Academy
of Pediatrics and Bill and Melinda Gates Foundation*

October 27, 2022 • 12-5:30 PM • Oberndorf Auditorium

PRESENTED BY:



**ELIZABETH
ROGERS, MD**

Professor of Pediatrics
Associate Vice Chair for Faculty
Development
Chief Experience Officer
UCSF - Benioff Children's Hospital San
Francisco



**JANNA PATTERSON,
MD, MPH, FAAP**

Senior Vice President
Global Child Health and Life Support
American Academy of Pediatrics



**EBUNOLUWA
ADEJUYIGBE, MBChB**

Professor of Pediatrics and Child
Health
Consultant Neonatologist
Obafemi Awolowo University Teaching
hospital Complex (OAUTHC)
Ile-Ife, Nigeria



**HARISH CHELLANI,
MD**

Professor & Principal Consultant
Department of Pediatrics
SJH & VMMC, New Delhi



**BJÖRN WESTRUP,
MD, PHD**

Senior Consultant in Neonatology
Founder and Director of the Karolinska
NIDCAP Training & Research Center
Astrid Lindgren Children's Hospital
Karolinska University Hospital



Culture of Care: Caring for Caregivers





Modern practice
environment
makes
professional
satisfaction more
challenging

Decreased autonomy

Reduced time at the bedside

Increasing barriers to balancing work
and personal responsibilities



Neonatal
Medicine is
ripe for
burnout

Demanding work schedules

Intense interpersonal interactions

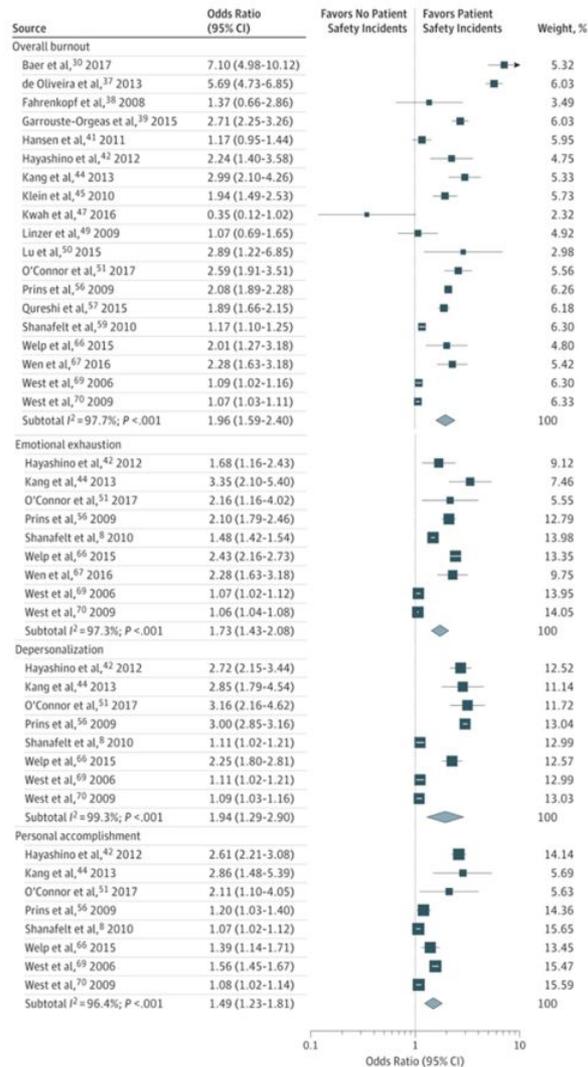
Frequent complex and high-stakes decisions in the face of uncertainty

Rapidly developing new technologies

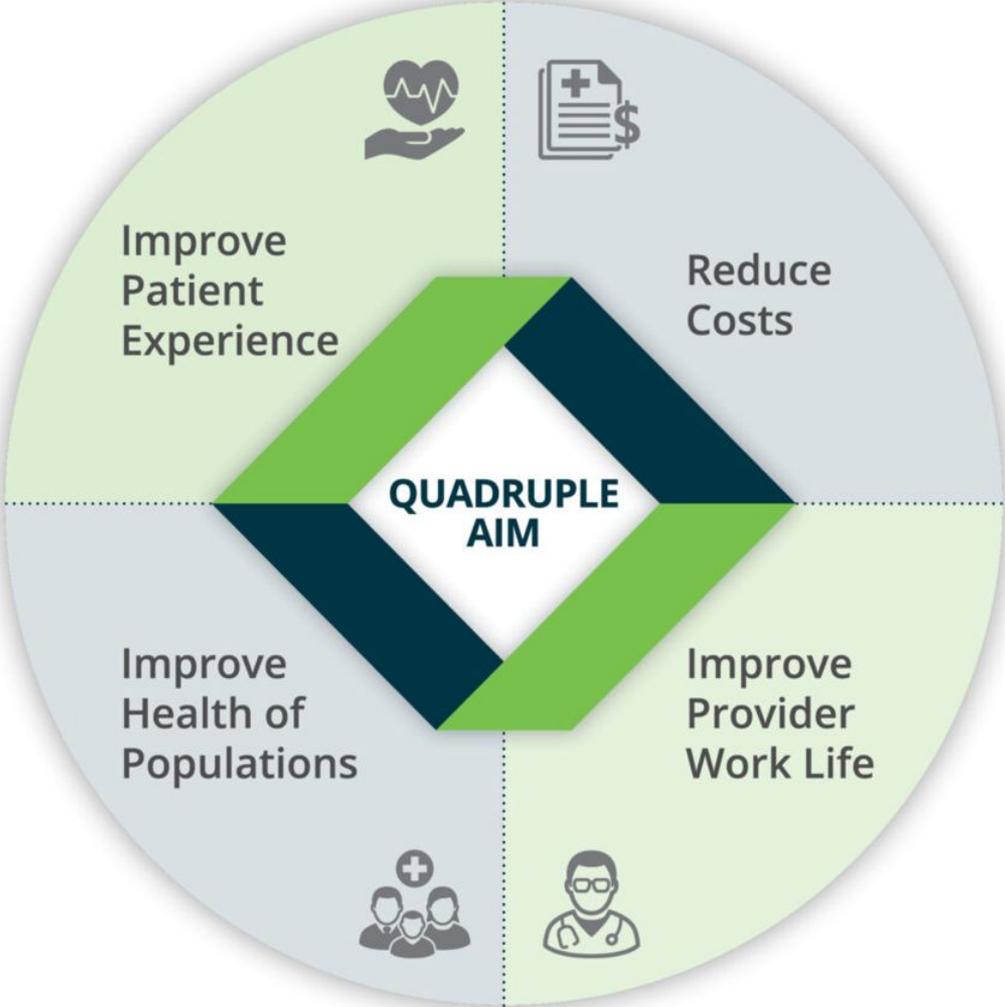
Experiencing suffering and death

D Tawfik, Provider burnout: Implications for our perinatal patients, Seminars in Perinatology, 2020.

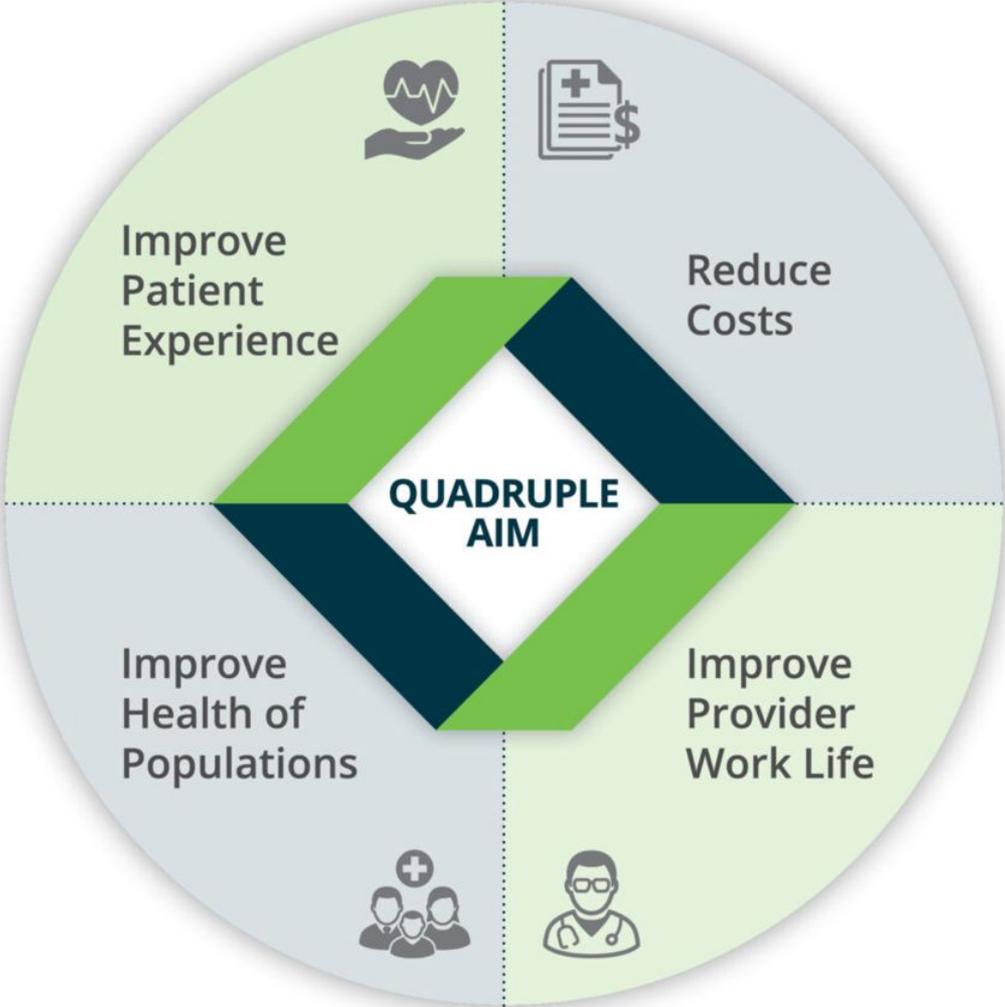
Provider well-being impacts patient outcomes

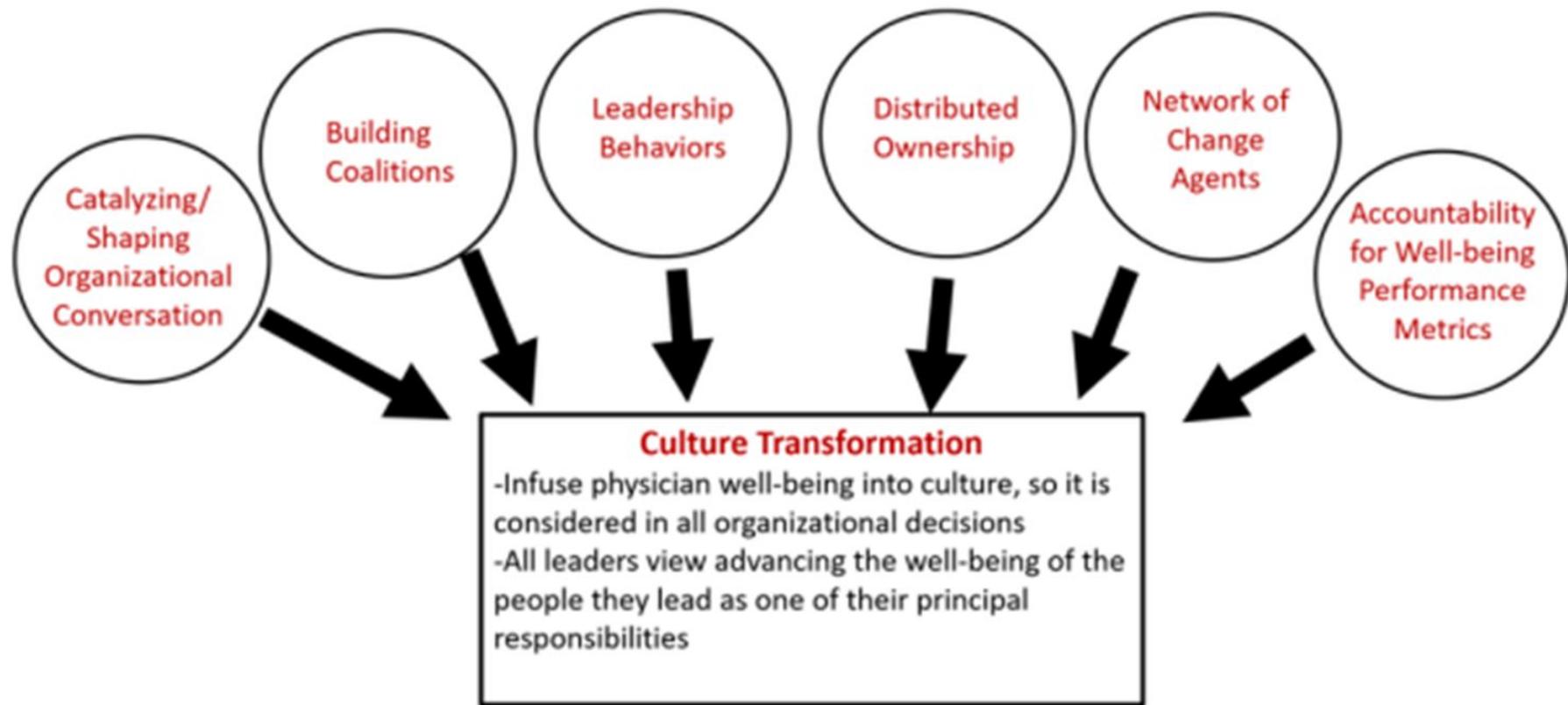


The
Quadruple
Aim



The
Quadruple
Aim









COCOON

Culture Of Care Observed in Obstetrics and Neonatology

We are seeking California-based **Obstetric & Neonatal staff** to participate in a survey on the culture of dyad-centered care.

We want to hear from all staff members including:

- **Advanced Practitioners**
- **Case Workers**
- **Lactation Consultants**
- **Midwives**
- **Nurses**
- **Physicians**
- **Social Workers**

Interested in connecting with the research team or participating? Please follow the QR code:



Contact: Cecelia Corson
corsonc@chop.edu



www.cocoonstudy.org



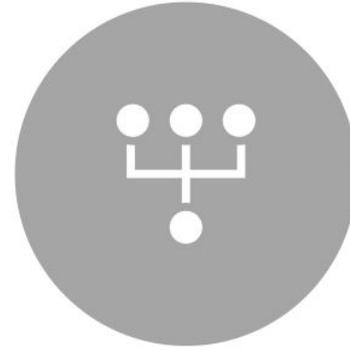
WHEN DOES SSC WORK
WELL IN YOUR UNIT?



WHAT IS THE SCAFFOLDING
THAT HAS FACILITATED A
SUCCESSFUL SSC EXPERIENCE?



BRAINSTORM THE BARRIERS
TO SSC IN YOUR DAILY
PRACTICE



FOR EACH ONE, USE THE “5
WHYS” TO GET BACK TO THE
ROOT CAUSE OF EACH BARRIER

FIXED MINDSET VS GROWTH MINDSET

Avoids challenges

Shy away from things you don't know

Unable to handle criticism or feedback

Gives up easily

"We don't do that here."

Believes failure is the limit of ability

My abilities are unchanging

When frustrated, gives up



Challenges help me grow

I can learn anything I want to do

Views feedback and criticism as an opportunity for growth

Resilient to adversity and strong mental fortitude

"How could we do that here?"

My abilities can develop and grow

Looks for the positive in every situation

Check-in



- Being intentional about cultures of care may improve outcomes for ourselves, our patients and families
 - All Care is Brain Care
 - Families as Partners
 - Caring for Caregivers
- Skin to skin care is an important quality target for improvements in both family partnership and neuroprotective care
- Equity, justice, and sustainability must be centered in neuroprotective care strategies
- We must learn (and unlearn) to acknowledge that we know and measure impact in myriad of ways

GOLDEN STATE
VALKYRIES





Thank you!

FCC Taskforce Webinar

The ABC's of Empathy, Hope and Clear Communication for NICU Parents



Terri Major-Kincade MD MPH | January 9th 2025

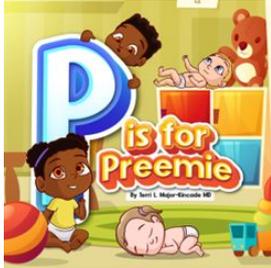
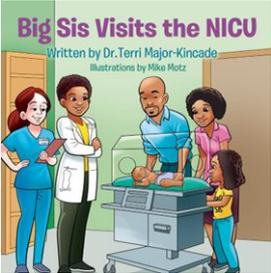


A vertical flyer for the FCC Taskforce Webinar. The background is dark blue with white snowflake patterns. At the top, it says "FCC Taskforce Webinar" in white. Below that, a white banner contains the date "JANUARY 19TH, 2025" and the time "11AM - 12:30PM PT". The main topic is "Optimizing Organization Mindset to Support Skin-to-Skin and Evidence-Based Neuroprotective Care". There are two speakers listed: Elizabeth Rogers, MD (SHE/HER), Professor of Pediatrics, Chief Experience Officer, & Associate Vice Chair of Faculty Development, UCSF Department of Pediatrics; and Terri L. Major-Kincade, MD, MPH, FAAP (SHE/HER), Associate Professor of Pediatrics, Medical Director Pediatric Palliative Care, UT Health Houston, McGovern Medical School, Children's Memorial Hermann Hospital. At the bottom, there are QR codes for registration and logos for sponsors: Rockit, Moody's, and the Family-Centered Care Taskforce logo.

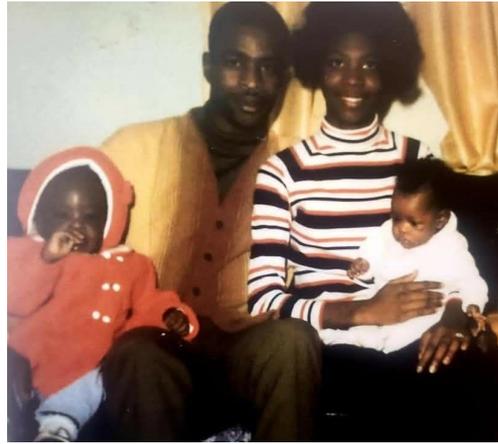
Objectives

- Identify 3 Core Principles of Empathy
- Illustrate 3 Barriers to Empathetic Care in the NICU
- Apply Core Empathy Principles to NICU Care
- Identify 3 Tools for Empathy at the Bedside

Who Am I?



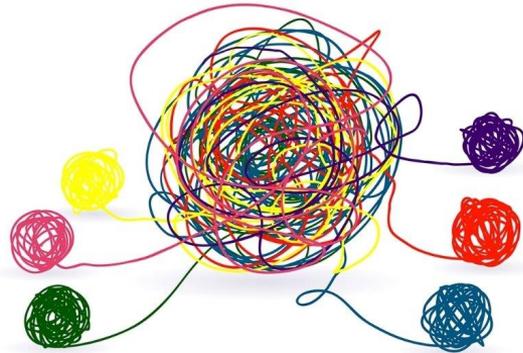
How I came to this work



Communication

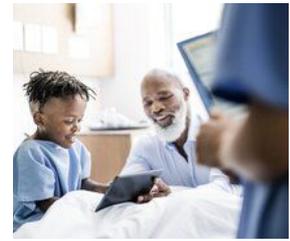
“The single biggest problem in communication is the illusion that it has taken place.”

- George Bernard Shaw



Barriers to effective communication

- **Systems Barriers**
 - Location
- **Clinician Perspective**
 - Timing,
 - Personal Biases
- **Family Perspective**
 - No Control over information dissemination



What's the Purpose of Rounds?
*A Qualitative Study Examining the Perceptions of
Faculty & Students*

Communication

- Coordinate Care
- Patient/Family communication
- Establishing rapport



Education

- Attending role-modeling
- Student presentations
- Establish autonomy
- Clinical decision-making



Assessment

- Attending observation, assessment, and feedback
- Establish expectations



Patient Care

- Formation of care plan
- Delivery of patient care

Hulland O et al . Nov 2017

Featured on #JHMChat on 11/27 @9PM EST

Journal of
HOSPITAL MEDICINE

Why is Effective
Communication
Especially Important for
NICU Families

A UNIQUE POPULATION WITH UNIQUE PROBLEMS

- Potential for Chronic Sorrow and Serial Bad News
- Potential for unintentional neglect and bias
- Potential for multiple delays and long- lasting complications



Serial Bad News/Chronic Sorrow

- **Why is the NICU like a war zone?**
 - Parents experience chronic sorrow related to **serial bad news**
 - Surrounded by **noises, alarms, sickness and death**
 - **Like war you don't know who is going to go home healthy and who is going to die**
 - **Serial trauma**
 - Unexpected delivery
 - Traumatic procedures
- **Risk for PTSD not related to how tiny baby is or how long baby stays in NICU but rather to parents coping style**
- **Family centered care, Support and Mentor Groups, Shared-Decision-Making** have been shown to be helpful in mitigating some of the parental distress



Unique Problems: Post-Traumatic Stress Disorder in NICU Parents

○ *Stanford University*

- *18 parents, after 4 months 3 had PTSD and 7 were at high risk for the disorder*

- *RJ, Shaw. Psychosomatics. 2006 May-Jun;47(3):206-12*

○ *Duke University*

- *30 parents, after 3 months 29 had 2/3 markers for PTSD*
- *16 parents had all three markers*

- *J Dev Behav Pediatr. 2009 Jun;30(3):193-205.*

● *Markers for PTSD*

- *hyperarousal*
- *flashbacks*
- *Nightmares*

- *More fathers experienced symptoms of PTSD after discharge than during the NICU stay*

- Overall, the findings indicate that *up to one-third of parent's experience PTSD symptomatology related to the NICU experience.* These results emphasize the importance of universal routine antenatal and postnatal screening for symptoms of PTSD to identify parents at risk of distress during the NICU experience and after discharge.

Unique Problems: Late Preterm Infant

- Potential for bias and neglect
 - “Implication that families are **lucky**”
 - Implication that it’s **no big deal**
 - **Unintentional neglect** when triaging for acuity
 - **Unprepared** for long-term complications



ABC's of Empathy for NICU Parents



Acknowledge



Breathe



Curiosity

Ortego Creative, November 9th 2021

<https://classdismissedpodcast.com/podcasts/abcs-empathy-make-stronger-educator/>

A

*How Do We Acknowledge
Parents in the NICU?*

Establish Rapport

Introductions

Language

Posture

Ask Permission

Introductions

Practice

What Your Patient is Thinking

Please don't call me mum

BMJ 2019 ;367 doi:

<https://doi.org/10.1136/bmj.l5373> (Published 09

October 2019)

Cite this as: *BMJ* 2019;367:l5373

Article Related Metrics Responses

Stephanie Nimmo

Twitter @stephnimmo

Stephanie Nimmo explains how being called mum by her daughter's healthcare team was disempowering and did not recognise the knowledge she brought to the team

Why I don't want you calling me "Mom."

And, as usual, I have probably overthought this. I often do. But, my goal is to empower moms at IEP meetings. And this gesture, albeit small, can have more impact than we might think.

1. It's awkward. Mom is my job title, depending on the setting. Do you refer to the other IEP meeting participants as "teacher" or "LEA" or "principal?" Probably not. Because it's *awkward*. "So, Occupational therapist, about this sensory goal..."



Don't Call Me Mum

PARENTS AS PARTNERS



KAROL MARKOWICZ

OPINION

Dear strangers: Don't call me mom

By Karol Markowicz

Published May 10, 2015, 7:07 p.m. ET



Don't call me Mom...How Parents Want to be greeted by their Pediatrician.....

- Study Question: To determine parent's expectations of pediatrician greetings and the frequency with which these expectations are met
- Population: 100 patients visiting General Pediatric Clinic Children's Hospital of Michigan
- Interviewed at the end of their medical encounter to determine expectations for greeting by physician
- 80% expected provider to shake hands, 70% did so...
- **88% wanted to be addressed by their name...only 14% of provider did so**

https://www.researchgate.net/publication/24248603_Don't_Call_Me_'Mom'_How_Parents_Want_to_Be_Greeted_by_Their_Pediatrician



Restricted access

| Research article

First published online March 31, 2009

“Don't Call Me ‘Mom’”: How Parents Want to Be Greeted by Their Pediatrician

[Ahdi Amer, MD](#), and [Howard Fischer, MD](#) [View all authors and affiliations](#)

[Volume 48, Issue 7](#)

<https://doi.org/10.1177/0009922809333973>



From: Should We Call You Mom and Dad? Caregiver Preferences and Pediatric Physician and Nurse Manner in Greetings

Hosp Pediatr. 2019;9(12):989-992. doi:10.1542/hpeds.2019-0170

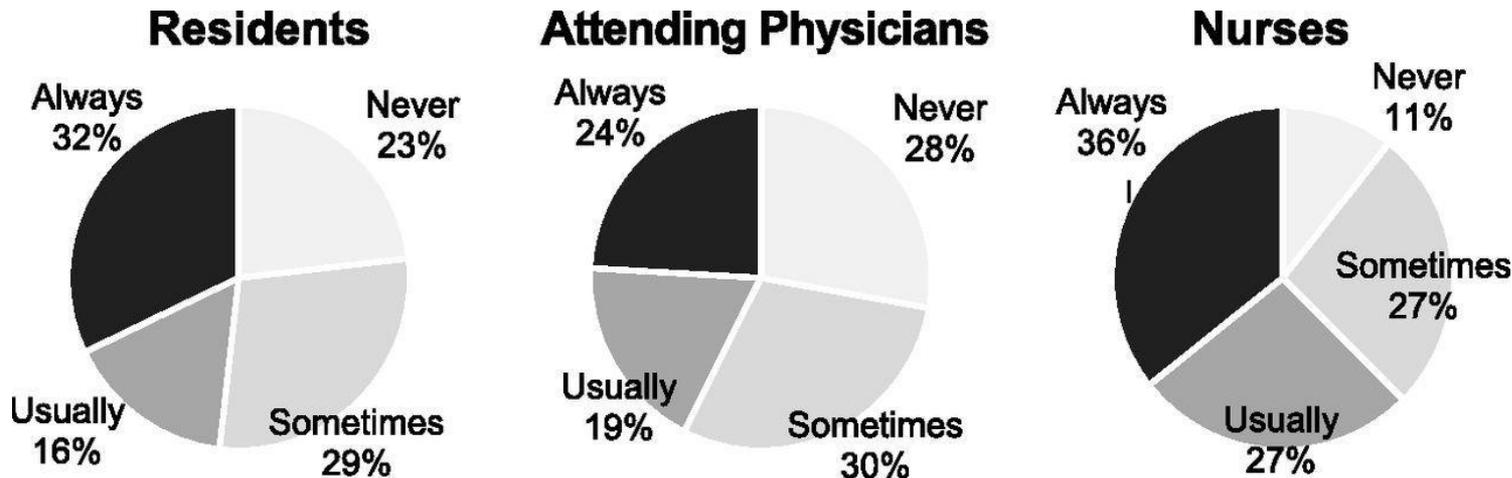
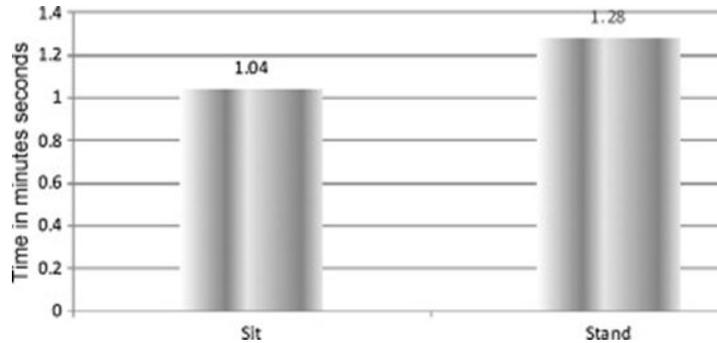


Figure Legend:

Caregivers reported how often members of the inpatient care team addressed them by their preferred name (n = 56). Blank responses were excluded from total percentages.

Posture: Consider **Sitting** vs. Standing if possible.....

- Patients perceive that the provider has spent more time in the encounter if the clinician is sitting rather than standing and report higher patient satisfaction scores.



CCBYNC Open access
Research Christmas 2023: Marginal Gains
Effect of chair placement on physicians' behavior and patients' satisfaction: randomized deception trial
BMJ 2023; 383 doi: <https://doi.org/10.1136/bmj-2023-076309> (Published 15 December 2023)
Cite this as: BMJ 2023;383:e076309 <https://www.bmj.com/content/383/bmi-2023-076309>

ORIGINAL RESEARCH
Open Access
Wall-mounted folding chairs to promote resident physician sitting at the hospital bedside
Blair P. Golden MD, MS, Sean Tackett MD, MPH, Kimiyoshi Kobayashi MD, MBA, Terry S. Nelson MSN, RN, NEA-BC, Alison M. Agrawal MHA, Jerry Zhang MHA, Nicole A. Jackson MS, Geron Mills BA, Ting-ila Lorigiano MD, MBA, Meron Hirpa MD, Jessica S. Lin MD, MBA, Trent Johnson MD, Aparna Sajja MD, Sarah Disney MS, FACHE, Shanshan Huang MBA, Jui Nayak MHA, Matthew Lautzenheiser MHA, Stephen A. Berry MD, PhD
<https://shmpublications.onlinelibrary.wiley.com/doi/epdf/10.1002/ihm.13271>



<https://www.santeestrie.qc.ca/clients/SanteEstrie/soins-services/Themes/Grossesse-ac-couchement/CHUS-Guide-Neonatalogie-ANG-2021.pdf>



<https://www.santeestrie.qc.ca/clients/SanteEstrie/soins-services/Themes/Grossesse-accouchement/CHUS-Guide-Neonatalogie-ANG-2021.pdf>

Posture: Parent Led NICU Rounds



<https://www.paediatricfoam.com/2019/07/parent-led-ward-rounds-on-a-neonatal-unit/>

ASK Permission.....



B

*How Do We Remember to **Breathe**?*

Pause and Embrace Silence



Pause and Embrace Silence



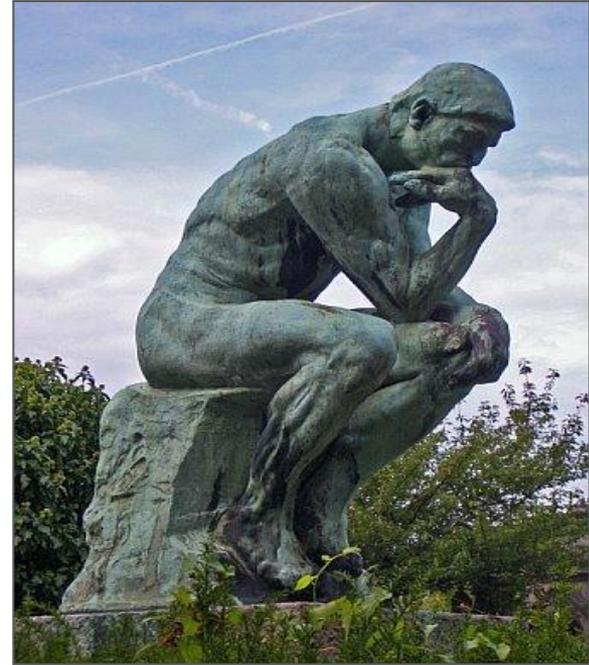
“Studies have shown that the patient normally speaks for an average of **18 seconds** before the doctor interrupts,”
“But if the doctor lets them speak for three to four minutes, they tell you 90 percent of what's wrong with them.”

When you speak, two channels are activated



Emotion

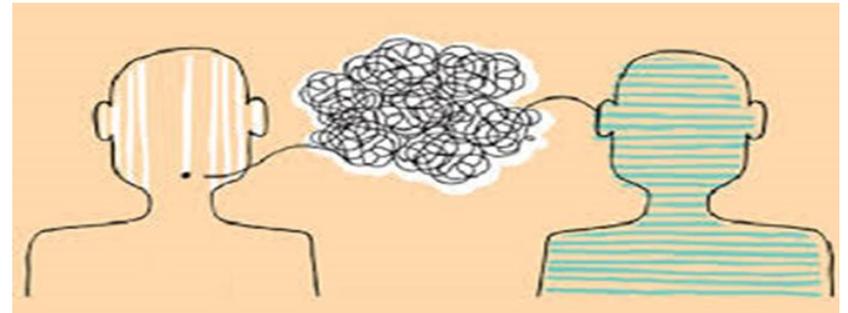
Faster & more powerful



Cognition

Words Matter-So Does Silence

- Hearing is **PASSIVE**
- Listening is **ACTIVE**
- **Listen more, talk less.**
- *It's hard because when we are talking, we are in control*
- *We are hardwired to listen*
 - *The average person can speak 125-225 words per minute , but we can listen up to 500 words per minute.*

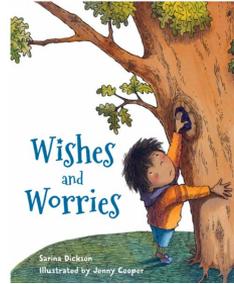


How Does Hearing Vs. Listening show up for NICU Families

- **One-Sided** Family Meetings
- **Predominantly Yes-No questions** rather than Open Ended Questions
- **Negative Labeling/Stereotyping/Perceptions**
 - Assertive vs. Aggressive
 - Appropriate Questions vs. Perception of Mistrust
 - Perception of Denial rather than understanding the Value of Hope or impact of Fear/Worries

Staying out of Judgement and Listening → Open ended questions

Be
Curious
Not
Judgemental



“Tell Me
More”
“Help Me
Understand
What are you most
worried About?”

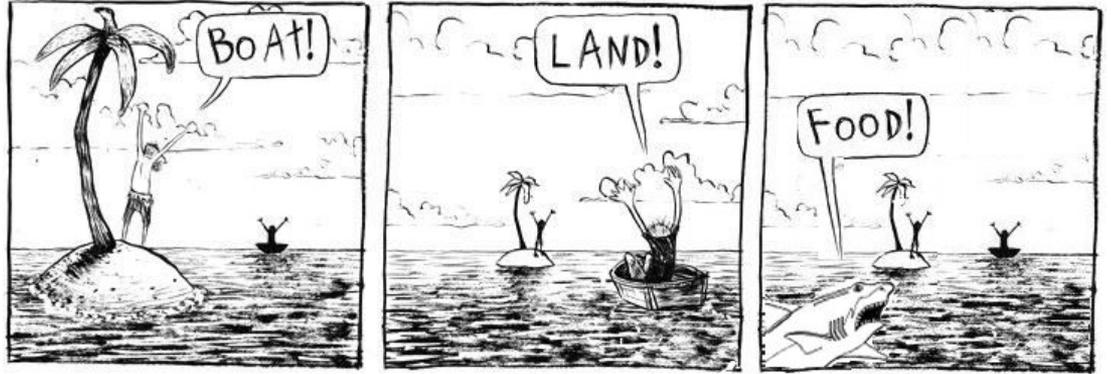
Empathy in Action

- Perspective Taking
- Communicating the understanding of another person's emotions



Perspective Taking

- The ability to understand the situation or concept from another person's point of view
- Putting yourself in someone else's shoes



What might perspective taking look like for NICU Parents?

- For NICU Families not minimizing concerns about unanticipated changes in plans or hesitancy for treatment recommendations
- Not minimizing concerns for bigger preemies in the setting of smaller preemies babies who might have more complex issues

G-Tube/Trach
Discussions

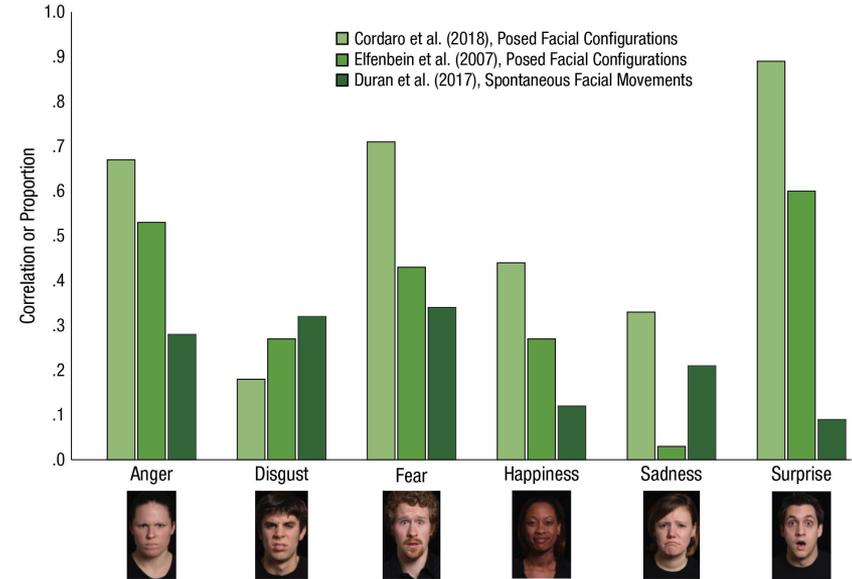
Perception of
Visitation
Patterns

Apnea

Feeds

Micro-Preemie Vs.
Bigger Preemie vs.
Term Babies

Recognizing Emotion in Another Person-READ THE ROOM



Barrett, L. F., Adolphs, R., Marsella, S., Martinez, A. M., & Pollak, S. D. (2019). Emotional Expressions Reconsidered: Challenges to Inferring Emotion From Human Facial Movements. *Psychological Science in the Public Interest*, 20(1), 1-68. <https://doi.org/10.1177/1529100619832930>

Fig. 7. Comparing posed and spontaneous facial movements. Correlations or proportions are presented for anger, disgust, fear, happiness, sadness, and surprise, separately for three studies. Data are from Table 6 in Cordaro et al. (2018), from Effenbein, Beaupre, Levesque, and Hess (2007; reliability for the anger category is for AU4 + AU5 only), and from Duran, Reisenzein, and Fernández-Dols (2017; proportion data only).

Communicating the understanding of another person's emotions

"When we *validate*, we communicate that we *understand and accept* the other person's emotions."

Diana Partington
DBT for Life: Skills to transform the way you live

@SufferingOptional

**Thank you for sharing
what
is most important you**

**I can only imagine how hard
this is for you and your family**

**Would it be helpful to have another
opinion?**

**You are a good parent. Thank you for being so
intentional and thoughtful with every decision.
We can feel your love for your child.**

NURSE Acronym for Empathy



Representative language

Naming

“It sounds like...”

Understanding

“I’m hearing you say...”

Respecting

“I am impressed that...”

Supporting

“I’ll be available for you...”

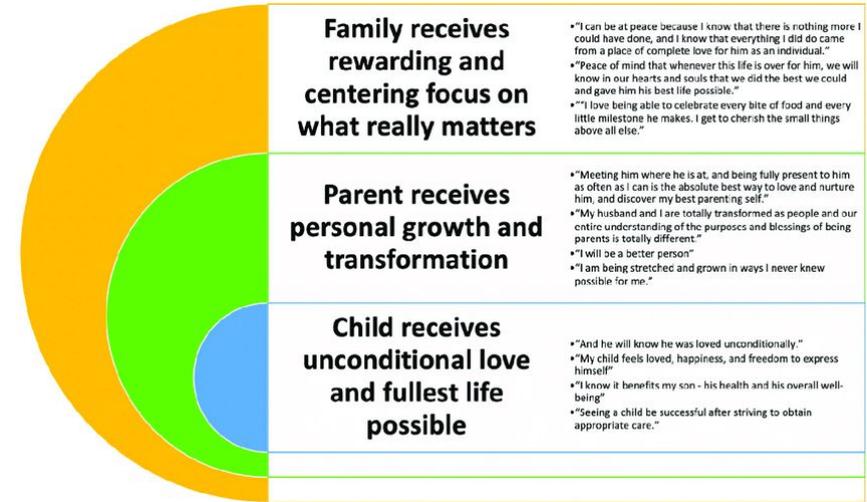
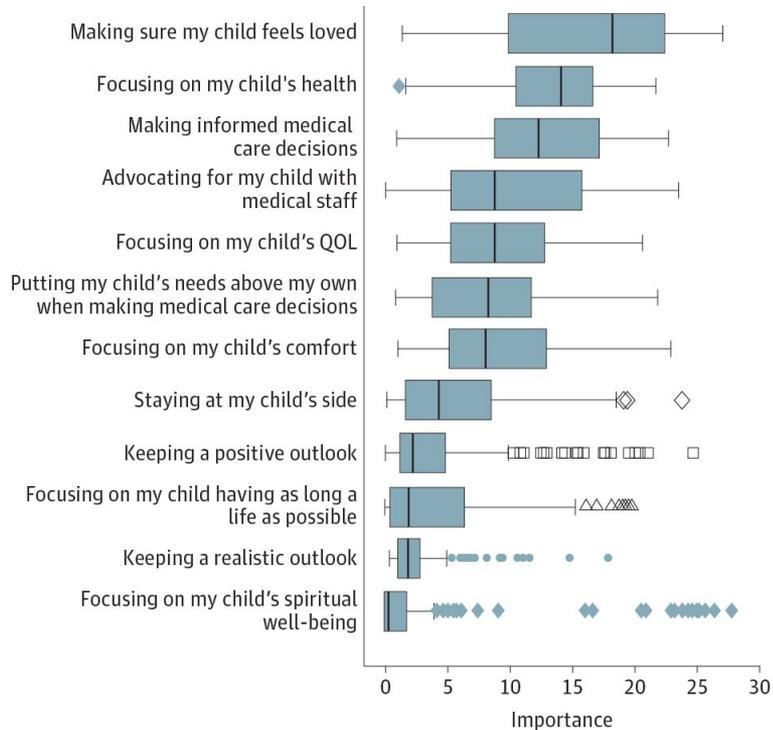
Exploring

“Tell me more about...”

Source: Pollak et al.¹⁷

Krimshtein, Nina S. et al. “Training nurses for interdisciplinary communication with families in the intensive care unit: an intervention.” *Journal of palliative medicine* 14 12 (2011): 1325-32 .

What are the benefits of personal good parent definition?

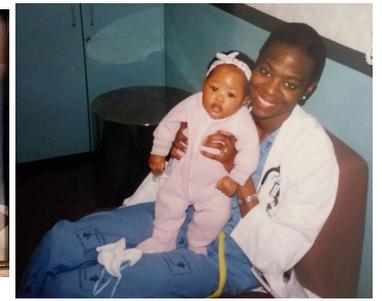


Weaver MS, Neumann ML, Lord B, Wiener L, Lee J, Hinds PS. Honoring the Good Parent Intentions of Courageous Parents: A Thematic Summary from a US-Based National Survey. *Children*. 2020; 7(12):265. <https://doi.org/10.3390/children7120265>

Feudtner C, Walter JK, Faerber JA, et al. Good-Parent Beliefs of Parents of Seriously Ill Children. *JAMA Pediatr*. 2015;169(1):39–47. doi:10.1001/jamapediatrics.2014.2341

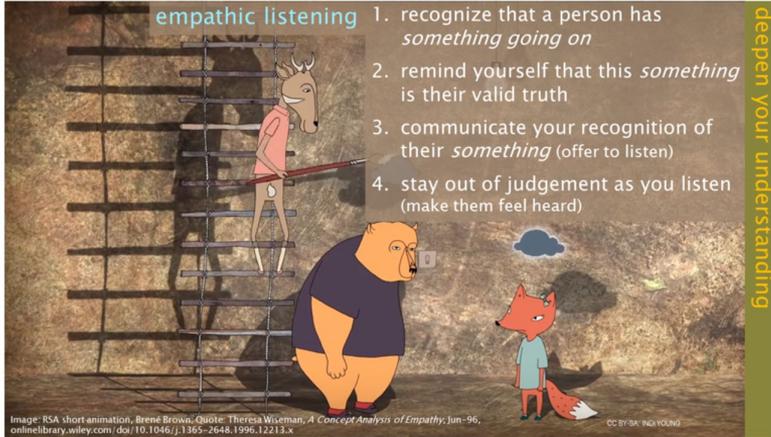
Parental Decision Making/Influences

- Healthcare Choices
- Diet
- Education
- Clothing
- Responsibilities
- Autonomy
- Self Expression
- Hobbies/Sports
- Friend Groups/Significant Others
- Career Choices



Summary:

ABC's of Empathy for Clear Communication for NICU Parents



ABC's of Empathy

1. Acknowledge
2. Breathe
3. Curiosity

NICU Barriers

1. Location
2. Timing
3. Family vs. Clinician vs. Hospital Perspectives/Policies

Tools for Empathy in Action

1. Language
2. Posture
3. Perspective Taking/Good Parent Beliefs
4. Open-Ended Questions
5. NURSE acronym for Empathy

<https://www.georgiancollege.ca/blog/student-life/mental-health-week-what-is-empathy-and-why-is-it-important/>

Questions

Thank You!!
😊



- Contact:
- [Email: terri.l.major@uth.tmc.edu](mailto:terri.l.major@uth.tmc.edu)

2025 Webinars

March 13th:

Erick Ridout, MD

Ellery Spencer, BSN, RN & Molly Fraust-Wylie

May 8th:

Kari McCallie, MD & Ashley Omwando, MBA

Lelis Bauza Vernon, S.Q.I.L. & Sue Bowles, DNP, APRN

July 10th:

Mary Coughlin, MS, NNP, NCC-E

Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW

September 11th:

FCC Taskforce Phase 4 Work

Lauren Ingledow

November 13th:

Deborah Buehler, PhD

Sue Ludwig & Christy Gliniak, PhD, OTR/L, CNT,
CPXP, NTMTC



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