Family-Centered Care in the SCN and NICU

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Proposed Neonatal Initiatives

- Neonatal Abstinence Syndrome 2.0
- Antimicrobial Stewardship in EOS/LOS
- Managing Tiny Babies
- Family-Centered Care
Involving the family in their infant’s care can improve infant outcome at and beyond discharge and improve family experience and clinician/caregiver satisfaction. Yet, many families face barriers and SCN/NICUs experience challenges in achieving quality FCC.

We propose three processes for continuous quality improvement:

1) welcome families into the care team - ensuring that families are respected as team members; incrementally participatory in their infant’s care; confident about care after discharge; and fully attuned to their infant’s personality;

2) develop tools to assess the domains of respect; communication; access; family integration into care; family confidence in and competency of care; and global family readiness for discharge; and

3) develop strategies to use these tools to improve these processes with each family.

• Each unit will be able to benchmark and improve the quality of their family-centered care and track infant outcomes.
Family-centered care is defined as a shared approach to the planning, delivery, and evaluation of healthcare that is based upon a partnership between healthcare professionals and family caregiver(s).

There are four essential domains of FCC:

1) Dignity and respect
2) Information sharing
3) Participation
4) Collaboration

Institute for Patient- and Family-Centered Care

Challenges of the SCN/NICU Mother

Often burdened with increased psychosocial, mental health, environmental, and socioeconomic challenges during pregnancy and after delivery that correlate with increased adverse outcomes. (Hawes 2016, McGowan 2017, 2019)

Mothers with mental health challenges (McGowan 2016, 2018):
- Self-report poorer readiness for infant discharge, less family support, increased concern about themselves and infant.
- Infant visit to ED more likely within 90 days after discharge.

Mothers with social risk factors (Medicaid, non-English speaking): (Vohr 2017, 2018; Liu 2018)
- Increased infant visits to ED
- Higher rate of infant rehospitalization
Risks to the SCN/NICU Infant

Biologic risk: Discrete medical morbidities that may cause brain injury or alter brain development

Proximal risk: Decreased parental involvement (deficit of touching, soothing, language and communication, interaction)

Distal risk: Socioeconomic, cultural, educational adversity; racism; impaired maternal mental health; poor extended family support.
Maternal Care in Animals

Study of rat mothers and pups: high licking and grooming (L&G) vs. low L&G

Pups exposed to high L&G compared to low L&G mothers exhibited
- Less fear
- Reduced hypothalamic-pituitary response to stress, persisting into adulthood

Cross fostering resulted in reversal of effects

Possible effects on pup epigenome (increased glucocorticoid receptor gene promoter in hippocampus)

Maternal care may program offspring behavior over the lifetime
Stroking Care by Human Mothers

Study of mothers with history of inter-partner psychological abuse and their infants

Maternal self-reports of frequency of stroking infants at 5 and 9 weeks

Results:

  Prenatal maternal depression associated with decreased infant physiological adaptability and increased negative emotionality at 29 weeks if mother reported low stroking (Sharp H et al PLoS One 2012)

  Prenatal anxiety associated with infant internalizing and anxiety/depression per Child Behavior Checklist High at 2.5 years if mother reported low stroking stroking vs. low stroking of infant study of rat mothers and pups: high licking (Sharp H et al Psychol Med 2014)

Results analogous to the animal study of L&G in rat mothers and pups
From 10 weeks gestation to term, the fetal brain undergoes a very complex sequence of maturation.

- Neurogenesis and proliferation
- Migration
- Myelination
- Synaptogenesis and pruning

Number of neurons increases from 13 billion at 5 months to 100 billion at term
Consciousness develops as connections are made between the thalamus and the cerebral cortex which transmit auditory and visual input to the cortex (24-32 weeks)

Receptive and adaptive to nuances in language at least as early as 32 weeks: vocalizations and “conversation turns”; most infant language input comes from parents
Environment for FCC

Provides appropriate physical space to encourage family caregiver involvement

**Advantages/disadvantages of single family rooms**

Facilitates optimal breast feeding

Encourages skin-to-skin care

Allows infant to discriminate touch (stroking, massage, vibration) and voices (talking, reading, singing) of caregivers

Promotes meaningful interactions between the clinician caregivers and the family caregivers (participation, reflective listening, education)
### Family Engagement QI Collaborative Key Driver Diagram

<table>
<thead>
<tr>
<th>Aim Statement</th>
<th>Primary Drivers</th>
<th>Secondary Drivers</th>
<th>Potential Change Concepts</th>
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<tbody>
<tr>
<td><strong>By August 2022, hospitals will improve family engagement in NICUs by:</strong></td>
<td><strong>Adequate and timely communication regarding infant medical care between staff and families</strong>&lt;br&gt;<strong>Measure:</strong> 1) Parental presence on daily rounds; 2) Timing of first family meeting; 3) Parent report of being informed consistently</td>
<td><strong>Language barriers and lack of family presence</strong></td>
<td><strong>Increase use of interpreter services often and early</strong>&lt;br&gt;<strong>Use of multi-lingual virtual platforms</strong></td>
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<td><strong>Comprehensive social services and supports for families</strong>&lt;br&gt;<strong>Measure:</strong> 1) Date of first social worker contact after admission; 2) Postpartum depression screening performed in the hospital; 3) Standardized assessment of unmet basic needs; 4) Parental report of social, depression screening and assessment of unmet basic needs</td>
<td><strong>Lack of timely and frequent family updates</strong></td>
<td><strong>Reduce parking cost; Provide public transportation vouchers; Minimize restriction of sibling visitation; On site childcare for siblings; Overnight accommodations for families; Provide meals as needed</strong></td>
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<td><strong>Family engagement in hands-on NICU care</strong>&lt;br&gt;<strong>Measure:</strong> Skin to skin and breastfeeding continuation (through day 7, 28, and discharge)</td>
<td><strong>Inconsistency of infant care plans among providers</strong></td>
<td><strong>Improve communication among medical consultants and primary team; improve communication among primary team and nurses</strong></td>
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<td><strong>Family participation in discharge planning</strong>&lt;br&gt;<strong>Measure:</strong> 1) Timing of initiation and completion of discharge teaching for families; 2) parental report of discharge readiness; safe sleep adherence post-discharge;</td>
<td><strong>Language barriers and lack of family presence</strong></td>
<td><strong>Increase use of interpreter services often and early</strong>&lt;br&gt;<strong>Use of multi-lingual virtual platforms</strong></td>
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<td><strong>Current social services available not comprehensive to address all needs</strong></td>
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<td><strong>Lack of bandwidth of social workers due to competing priorities</strong></td>
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<td><strong>Lack of standardization of procedures to assess for mental health and unmet basic needs</strong></td>
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<td><strong>Language barriers and lack of family presence</strong></td>
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<td><strong>Families and NICU staff have unclear expectations about parental role in the NICU; lack of parental empowerment</strong></td>
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<td><strong>Lack of access to hospital grade pumps; restrictive policies for skin-to-skin care</strong></td>
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<td></td>
<td><strong>Language barriers and lack of family presence</strong></td>
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<td><strong>Lack of shared decision making in discharge planning</strong></td>
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<td><strong>Compliance with safe sleep practices in NICU</strong></td>
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**Chart abstracted measures**

**Family reported measures**

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*FPQC*
Opportunities for Practice Evolution

Assess and address maternal adverse mental health and stress

- Decrease both maternal and infant stress

Identify and address needs of family and infant

- Facilitate visitation
- Improve communication
- Integrate family into care discussions and decisions
- Provide culturally sensitive environment

Encourage active maternal involvement in infant care

Improve transition to home processes
Multidimensional opportunity to improve FCC
Centerpiece QI initiative: Skin-to-skin care
Identify areas of strength and weakness in your ability to encourage FCC in your unit
Target one or two interventions among the 4 domains that are high opportunity (realistic and feasible in your environment): browse the toolbox!
Coaching calls
We need your feedback to refine everyone’s efforts!
PAIRED Pilot: Skin-to-Skin Care (SSC)

Definition: skin-to-skin or chest-to-chest contact between an unclothed infant and their family caregiver’s bare chest. Also called kangaroo care.
Benefits of SSC – Mother-Infant Dyad

- Improved bonding
- Increased oxytocin
- Improved milk production
- Improved pain management
- Satisfaction with infant care
- Decreased maternal depression, anxiety, guilt
Benefits of SSC - Infant

**Improved**

- Autonomic function & neuroregulation
- Neurodevelopment
- Cerebral volumes
- Cognitive skills
- Oxytocin levels
- Weight, length, head circumference growth
- Pain management
- Breastfeeding at discharge
Benefits of SSC - Infant

Decreased

- Physiologic stress responses
- Motor functional deficits
- Hospital length of stay
- Mortality
- Infection/sepsis
- Hypothermia
Recommended by World Health Organization, American Academy of Pediatrics, Academy of Breastfeeding Medicine, Neonatal Resuscitation Program, among many others.

- Reliant on unit-specific guidelines

But this should be standard of care! A prescribed medication!
Barriers to SSC - Family

- Fear
- Stability
- Availability
- Pain
- Logistics
- Education
How we can help with barriers?

• **LOOK** for them!

• **ASK** about them!
  • Ask families
  • Ask staff

• **EDUCATE** about them!
  • Educate families
  • Educate staff
Use Resources
Primary Aim:

“For each participating NICU to achieve a 20% increase from baseline in the percentage of infants who receive skin-to-skin care from at least one family caregiver within 3 days of clinical eligibility as defined by individual unit protocols by June 2023.”
Change Ideas

Encourage family caregiver participation in early SSC
  • Develop SSC eligibility guidelines

Create a culturally sensitive environment for SSC
  • Cultural humility
  • Chairs
  • Access to food and water
  • Privacy

Educate on the benefits of SSC
  • Families and staff
Initiate competency training on SSC
  • For families and staff
  • For seated and standing infant transfers
  • Mock up infant transfers

Consult families to help revise policies that limit family interaction with infants

Standardize documentation of SSC episodes

Photos used with permission
How can FPQC help?

Provide a useful toolkit and resources
- Key driver diagram
- Change ideas
- Educational materials
- PDSA samples
- Metric ideas

Give rapid data feedback for tracking progress
- Monthly reports

Support monthly coaching calls
- Share successes
- Advice on challenges and barriers
- Updates
- Receive consultation/assistance
### Key Driver Diagram

**PAIRED Pilot**

<table>
<thead>
<tr>
<th>AIM</th>
<th>PRIMARY DRIVERS</th>
<th>SECONDARY DRIVERS</th>
<th>PBPs</th>
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<tbody>
<tr>
<td></td>
<td>Participation</td>
<td>Educate caregiver(s)/family to become active participants in the care of their infant from admission to discharge.</td>
<td>• Encourage caregiver participation in early skin-to-skin care.</td>
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<td></td>
<td>Dignity and Respect</td>
<td>Provide caregiver(s)/family with appropriate and increasing direct care opportunities.</td>
<td>• Include of families in daily rounds/creation of daily care plans/handoffs.</td>
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<td>Collaboration</td>
<td>Acknowledge that each infant and family member is an individual. Incorporate family knowledge, values, beliefs and cultural backgrounds into the planning and delivery of care.</td>
<td>• Provide early and continuing lactation support to promote breastfeeding.</td>
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<td>Information Sharing</td>
<td>Establish a culturally sensitive environment in which family members feel respected and that fosters anticipatory and effective communication with and trust from caregiver(s)/family.</td>
<td>• Revisit and revise policies that limit caregiver interaction with infant.</td>
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<td>Encourage collaboration with families, caregivers and unit leaders in the development, implementation, and evaluation of policies and procedures; in educational programs; and in protocols for family participation in care.</td>
<td>• Create a culturally sensitive environment supportive of skin-to-skin care (reclining chairs, access to food and water, privacy).</td>
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<td>Provide families with complete, accurate and unbiased information and graduated education throughout the NICU stay to allow effective participation in care, to optimize decision-making, and to enable caregivers to become competent primary caregivers for their infant(s).</td>
<td>• Identify infant and caregivers by appropriate names in all interactions.</td>
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<td>• Consult families, revisit and revise policies that limit caregiver interaction with infant (protocols regarding skin-to-skin care, holding, visitation, signage, etc).</td>
<td>• Celebrate milestones and transitions.</td>
</tr>
</tbody>
</table>

**SUPPLEMENTAL**

- By 6/2023, each NICU will achieve a 20% increase from baseline in the percentage of infants who receive skin-to-skin care from at least one caregiver within 3 days of clinical eligibility as defined by individual unit protocols.
- By 6/2023, parental surveys will demonstrate a 20% improvement from baseline in the perception of the culture of family centered care in each NICU as averaged across all 4 domains.

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*Family-centered care is defined as a shared approach* to the planning, delivery, and evaluation of healthcare that is based upon a partnership between healthcare professionals and families of patients. There are four essential domains of FCC: 1) family participation in care, 2) dignity and respect, 3) family collaboration, and 4) information sharing.
Video: How to Transfer Babies

https://www.youtube.com/watch?v=VOjGhwMuWFU&feature=emb_logo
See the PAIRED Toolkit for more ideas!
References

- Conde-Agudelo A, Diaz-Rossello JL. Kangaroo mother care to reduce morbidity and mortality in low birthweight infants (Review). Cochrane Library. 2017
Thank You

Questions?