Family Integrated Care: Quality Improvement; Small Changes = Big Gains

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I have nothing to disclose

I am not promoting the off label use of any products or any proprietary products
Who am I?
Objectives

• Identify promoters and barriers to active parent involvement in the NICU

• Apply the Model for Improvement to a common clinical challenge: families routinely removed from the care of their infant in modern NICUs

• Identify essential factors for success in making improvements in family centered care in the NICU
What Does Family Integration Really Mean?

FAMILY CENTERED CARE
FAMILY INTEGRATED CARE
Family Centered Care in the NICU

• Shifts the attention from the disease alone to the patient in the context of the family and community
• Approach to health care delivery grounded in mutually beneficial partnerships among health care providers and families
• Recognizes vital role families play in ensuring health/well-being of their babies
• Shapes policies, programs, facility design and staff day-to-day interactions
• Most NICUs are at this point
Family Centered Care Core Concepts

- Respect and dignity
- Information sharing
- Participation
  - Family determines
- Collaboration
  - At bedside
  - Policy development
  - Education

All photos used with permission; Salem Health an OHSU Partner
Family Centered Care Attributes

• Aspects of support
  – Parent education
  – Parent participation in decision making
  – Parent presence and participation in care-giving
  – Family presence and support—siblings, grandparents
  – Support for families (and staff) when an infant dies
  – Transition to home

Family Centered Care Issues

- This all sounds so great . . . what else is needed?
- Change in mind set: Continued adherence to premise that only NICU professionals with special skills can provide care to the infant
- Parents relegated to supportive role
- Variable/inconsistent implementation
- Families and staff need support
  - Poor understanding of concepts, goals, importance
  - Lack of standards
  - Lack of resources
  - Lack of social support (unlike Sweden)
Family Integrated Care

• Family provides all except the most advanced medical care for their infants with support from the medical team

• A paradigm shift in approach to NICU care
  – Likely also applicable to pediatrics, palliative care, geriatrics and chronic care
Changing the core structure of the unit (and the infant)

• Epigenetics is the study of cellular processes that determine gene function
• Development is a dynamic process that involves interplay between genes and the environment
• Quality of postnatal environment shaped by parent-infant interactions
  – Impact growth, survival, divergent developmental trajectories and long term neurobiology and behavior
  – Can affect the phenotype across generations
• Epigenetic factors (e.g. DNA methylation, histone changes) impact gene expression and have a critical role in parental care effects
  – Much of the research evidence is from animal models
  – Emerging support for this in humans

• Kundakovic and Champagne (2014): Early-Life Experience, Epigenetics and the Developing Brain
Decreased Maternal Anxiety = + effect

- A systematic review and meta-analysis
  - RCTs between 1990-2011, published in English, children born preterm
  - Preventive intervention started before age 3 years
    - Involved parents
    - Intervention included at least one session in the community
  - Assessed benefits to babies and parents
  - Three interventions
    - Psychosocial support
    - Education
    - Developmental intervention delivered by the mother
- Improved maternal anxiety = improved infant outcomes
  - Focus on maternal anxiety may be more important than focus on maternal stress
- Three interventions with positive effects on maternal depression
  - Victoria Infant Brain Studies
  - Creating Opportunities for parent Empowerment
  - Mother Infant Transaction Program
- More than education needed to improve parent sensitivity/responsiveness
  - Measurement depends on baby’s skills as well as the parent’s
- More than education needed to lower parental stress

History of the change
Estonia

- 1979 Tallinn Children’s Hospital in Estonia established the use of a FICare-type model, then coined Humane Care Model, due to a shortage of NICU nurses.
- Developed out of necessity.
- 24-hour care by the mother, minimal use of technology, and little contact between the baby and medical and nursing staff.
- Before/after comparison (non-randomized) of 159 infants showed a 37% improvement in weight gain in the first 20 days of life.

Sweden

- Largely based on the work in Estonia
- RCT (unblinded)
  - Standard Care vs. Family Care
    - FC = Parent stayed 24 hours/day
  - Less than 37 weeks 0 days
  - Randomized on admission
    - Intention to treat analysis
    - 183 FC, 183 SC
  - Outcome Shorter hospital stay: 5.3 days shorter (27.4 vs 32.8, p = 0.05)
    - Especially true at earlier gestations (less than 30 weeks)
      - 10.1 days shorter (56.6 vs 66.7, p = 0.02)
  - Lower incidence moderate to severe BPD
    - 3 vs 11 infants (adjusted OR = 0.18 (0.04-0.8))

- Ortenstrand et al (2010): Stockholm Neonatal Family Centered Care Study
Based on the work in Estonia and Sweden Mount Sinai Hospital, Toronto, Canada

- 31 FICare infants were matched 1:2 with control infants ($n = 62$)
- Rate of weight gain was significantly higher in FICare group ($p<0.05$)
- Significant increase in rate of breastfeeding at discharge ($p<0.05$)
- Significant decrease in mean Parental Stress Scale scores (admission vs. discharge) ($p<0.05$)
  - Control group score variance was not found to be significant
The Vermont Oxford Network was our inspiration and vehicle.
VON: Virtual Video Visit, May 2014

Chapter 2
Shifting Paradigms:
Moving From "Visiting" to Parenting in the NICU
Canada- Phase 2

- Cluster randomized controlled trial among infant born ≤ 33 weeks gestation
- 19 Canadian Level 3 NICU, 6 Australian Level 3 NICU, 1 New Zealand Level 3 NICU
- Target sample size 675 in each arm
- April 2013-Aug 2015 (anticipated); now 2017

**FICare**
- Parents taught to provide most care
- Parents present minimum 6 hours/day
- Supported by nursing staff
- Supported by veteran parents
- Supported by program coordinator
- Offered education sessions

**Control Group**
- Standard NICU care provided

**Primary Outcome**
- Infants’ weight gain at 21 days after enrollment
  - Student’s t-test

**Secondary Outcome**
- Breastfeeding
- Clinical outcomes
- Safety
- Parental stress/anxiety
- Resource use

What’s next?

Family-Centered Developmental Care
Newborn Intensive Parenting Unit – NIPU
“In the ideal NICU, psychosocial support of both NICU parents and staff should be goals equal in importance to the health and development of babies.”

Family Centered Developmental Care

- Treat parents as full partners
- Offer space for 24/7 care
- Educate and train parents to provide developmentally appropriate care
- Include neonatal/maternal therapists (psychologist)
- Offer peer support
- Teach parents to recognize behavioral signs of stress, relaxation, feeding cues
- Train staff and offer ongoing supportive staff education
- Facilitate early, frequent, prolonged skin-to-skin contact

- Potentially better practices published as recommendations from the National Perinatal Association (Dec. 2015)
ENDORSED by 32 professional and parent support organizations
Neonatal Intensive Parenting Unit

• Improved parent-infant bonding
• Improved infant outcomes (especially brain-sensitive outcomes such as IVH, NDI, BPD, EUGR)
• Empower parents
• Lowered rates of parental depression, anxiety, acute stress disorder, and PTSD
• Improved parent and staff experience and satisfaction
• Continuity of care provided from antepartum through post-discharge
• Shortened hospital stay
Parent Involvement in the NIPU

- The NIPU engages parents as partners
  - In designing unit services, philosophy and care practices, as well as in designing the space
  - As participants in improvement work
  - In the QI process, including a parent-reported measure in every PDSA cycle and test of change
- Everyone in the NIPU, regardless of status, is looking out for the baby, the family and each other
Space is ideal, but not a requirement
Questions so far?

Next: Our culture change journey
Salem Hospital
Know your adjacent possible

Improvement is incremental

Take inventory of where you are now
Salem Health an OHSU Partner

Only Hospital in Salem
27 bed, Level 3
3500 deliveries
400 NICU admissions/year
• 24 hour parent access 2005
• Parent Advisory Council 2006
• Parents participating in our VON NICQ collaborative 2007
• Parent on NICU governance council 2013
• Strong emphasis on early, frequent and long periods of skin to skin involving both parents
• Aggressive work on S2S as part of VON collaborative 2012
• Active Parent Mentors
• Parent resource center
• Daily multidisciplinary rounds with parents
Time from Birth/ Admission to First Successful Skin to Skin

- **Intervention:** New Guidelines, Education, and Skin-to-skin standardized
- **Intervention:** Learning tool

- 2012 baseline
- 4/2013 measurement restarted
- 6/2013 learning tool
Layout prior to Family Integration
Know where you are coming from . . .

and where you want to go
Have a SMART AIM

What are you trying to accomplish?

• “Perfection Is The Enemy Of The Good”

• You don’t need a SMART Aim to get started

• “Let’s be like Sweden”

• Specific, Measurable, Attainable, Relevant, Timely

 ✓ Family Integrated Care will be the standard model of care in our NICU for 100% of our families by January 1, 2016
How will we know a change is an improvement?

Measurement

• Can be difficult to identify good measures
  – Qualitative vs Quantitative

• Outcomes
  – Family Satisfaction (survey)
  – Skin to Skin Time
  – LOS

• Processes
  – Are we doing what we say we are doing?
    • Using a checklist around admission
    • EMR review
    • Results are often surprising
“Just Do It” - what can you do by next Tuesday

Small Tests of Change
PDSA Cycle for Learning Improvement

**Plan**
- Objective
- Questions and predictions (why)
- Plan to carry out the cycle (who, what, where, when)

**Do**
- Carry out the plan
- Document problems and unexpected observations
- Begin analysis of the data

**Study**
- Complete the analysis of the data
- Compare data to predictions
- Summarize what was learned

**Act**
- What changes are to be made?
- Next cycle?
“Testing before implementing is almost always important for successful implementation”
The Bed

Our first Test of Change (TOC) following our inspiration
First PDSA: Adult Bed TOC #1
Organize a small TOC
Stick to the plan
Communicate WELL
Solicit feedback
Listen to feedback
Organize the next test

Plan
Do
Study
Act
Kangaroo Wrap

Response to Nursing Concerns
PDSA: Kangaroo Wrap, TOC #2
PDSA: Adult Bed + Wrap, TOC #3
Adult Bed in Other Rooms, TOC #5
Adult Bed + Twins on CPAP, TOC #7
Team Solution . . . Critical Mass
The Bed Effect – Video
FIC Guidelines
Version 1 - Task Oriented

NG Feeds

Parent Responsibilities
- Second person to check milk with RN
- Confirm milk is an appropriate temperature
- Confirm volume to be administered is accurate
- Hold feed a appropriate level
- Monitor for tolerance

Nursing Responsibilities
- Double check milk with parent
- Double check volume of milk to be administered with parent
- Check position of NG/OG
- Chart feeding

http://www.mountsinai.on.ca/care/nicu/family-integrated-care
Development of FIC Guidelines: Staff Engagement
Version 2 - Following Staff Input

Oxygen
Parent responsibilities based on Flight Plan
- No manipulation of oxygen concentration (Admission)

Monitors
Parent responsibilities based on Flight Plan
- No manipulation of alarm limits (Admission)

Medications
Parent responsibilities based on Flight Plan
- Communicate the purpose of routine medications (Getting Better)

Tube Feeds
Parent responsibilities based on Flight Plan
- Second person to check milk with RN (Early Stay)
- Hold feed at appropriate level (Early Stay)
- Confirm milk is an appropriate temperature (Getting Better)
- Confirm volume to be administered is accurate (Getting Better)
- Monitor for tolerance (Getting Better)

Spells
Parent responsibilities based on Flight Plan

Oral Care
Parent responsibilities based on Flight Plan
- Oral care with mother’s milk during each care
- All baby is breast or bottle feeding at least 10 days

Skin to Skin Care
Parent responsibilities based on Flight Plan
- Possible during NICU stay when

Temperature
Parent responsibilities based on Flight Plan
- Change at the beginning of care time prior
- Temperature the nurse (Early Stay)
Phases of NICU stay

- Admission
  - My Needs
    - Calm & Soothe
  - Temperature
  - Diapering
  - Mouth Care
  - Feeding Plan
  - My Development
  - Care Times

- Early Stay
  - Getting Better
  - Grow & Feed
  - Preparing for Home

- Follow up Provider
  - Transportation to appointments: Yes
- Anticipated Discharge
  - This Week: No
- Newborn
  - Screens: No
- Off Feed
  - Completed: Yes
- Breast Pump for Home
  - Not Needed: No
- Items for Home
  - Other: Yes
- WIC
  - Does not meet criteria: No
- Immunizations
  - "Other:" Yes
- Palivizumab (Synagis)
  - Does not meet criteria: No
  - Meets criteria: Yes
- Influenza/Pneumonia
  - Vaccination: Yes
- Smoking Cessation
  - Tobacco: Yes
- Developmental Follow up Clinic
  - Does not meet criteria: No
  - Meets criteria: Yes
- Nutrition Follow up
  - "Other:" Yes
- Public Health Nurse
  - "Other:" Yes
  - "Other": Yes
- Early Intervention
  - "Other:" Yes
  - "Other": Yes
- Eye Exam
  - "Other:" Yes
  - "Other": Yes
- Medical Follow up
  - "Other:" Yes
- Family Concerns
  - "Other:" Yes

My Flight Plan for Home
My Name: ____________________
Birth: ___/___/____ Weight ________ Gestation ________
Discharge: ___/___/____ Weight ________ Gestation ________
Early Stay

Pumping:
- If you are providing breast milk, pump every 3 hours (or per lactations recommendations)

Bathing:
- Ensure water temperature is safe
- Wash in the direction of head to toe with liquid soap
- Rinse and dry thoroughly

Monitors:
- Understand your baby's vital signs and alarms

Oxygen:
- Call for assistance if CPAP needs adjusted
- Adjust low flow prongs on face as needed (Nasal Cannula or High Flow Nasal Cannula)

Skin to Skin:
- Stay awake during skin to skin for infant safety due to risk of suffocation

Spells:
- Recognize spells
- Provide stimulation
- Call for assistance

Temperature:
- Obtain a temperature at the beginning of care time prior to completely unwrapping baby
- Report temperature to the nurse

Tube Feedings:
- Second person to check milk with RN
- Hold feed at appropriate level

Medications:
- Know your baby's medications: reason for taking, side effects, timing
Best Family Experience

Breast feeding
- Early, regular pumping
- Lactation support
- Breast + gavage
- Minimal bottles to meet nutritional needs
- Baby Friendly
- Good communication

Discharge Readiness
- Flight Plan
- Standard teaching subjects + individual to meet needs
- FIC
- Anticipatory guidance
- Weekly discharge rounds
- Good communication

S2S time
- Proactive S2S support
- S2S in OR
- Kudder Wrap
- Clear expectation
- Good communication

Parents As Active Parents
- Increase parents & family’s presence with baby
  - Adult bed
  - Meals
  - FaceTime
- FIC
- Parent mentors
- Good communication
Skin to Skin hours/baby/day 2013-2016

QI: time to first S2S  QI: early FIC  QI: FIC Year 2  QI: micropremie
Ongoing Parent Involvement

Parent

Our NICU team knows how overwhelming this experience can be. During your stay you are given many educational resources, care instructions and other types of paperwork. This “pouch” is here to help you store all the information we provide you with while keeping it close at hand. Please feel free to use it to store these resources in one easy to access, organized spot. We want to help ease your stress as much as possible, so ask questions, let us know what you need, and remember that we are here for you as well as for your little one(s).
Success Essentials

- Have a great team and keep it great
  - Meet frequently (use your smart phones)
- Get your organizational and NICU leadership on board
- Know and use the evidence
- Know how to use the Model for Improvement
  - Or whatever your institution uses
  - But don’t be a slave to it
- Have some idea what you are aiming for
- Know your “adjacent possible”
  - Improvement is incremental
- Test your change ideas
- Communicate like crazy
- Engage with your skeptics
- Be resilient and be persistent
Reading and Knowledge Essentials

**Family Centered Care:**


**Quality Improvement:**

Additional References


• Macdonell, K., Christie, K., Robson, K., et al. (2013). Implementing Family Integrated Care in the NICU; Engaging Veteran Parents in Program Design and Delivery, 13(4); 262-269.


THANK YOU!
ANY QUESTIONS?