THE LONG ROAD HOME: SUPPORTING NICU FAMILIES

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Fairview Ridges Hospital NICU Statistics

- **General Statistics:**
  - Level III NICU
  - Care for babies 30 weeks gestation or greater
  - Average number of families per year: ~300-350
  - Approximately 10-12% of infants go to NICU
  - Average length of stay: 20 days
  - Common diagnoses: prematurity, infection (r/o sepsis), respiratory distress and hypoglycemia (poor feeding)
Postpartum Mental Health and the NICU
General Postpartum Statistics

- Percent of postpartum mothers who experience
  - Depression: 15%
  - Anxiety: 10%
  - OCD: 3-5%
  - PTSD: 9%
  - Depression in Dads: 10%

(Postpartum Support International, 2017)
NICU Postpartum Statistics

- 380,000 babies a year are born premature in the United States (March of Dimes, 2017)
- Percent of postpartum mothers with infants in the NICU who experience:
  - Depression: 28%-70% (Mounts, 2009)
  - PTSD symptoms: 15-53% (Binder, et al., 2011)
    - up to 49% report lingering symptoms of PTSD up to a year post discharge (Pierrehumbert, et al., 2003)
    - One study found 17% of mothers indicated clinical levels of PTSD two to three years after the birth (Ahlund, et al., 2009)
- Increased likelihood of early onset of parental distress including Acute Stress Disorder (Lefkowitz et al., 2010)
- Increased levels of anxiety and depression symptoms in fathers of NICU babies (eCandelori et al., 2015)
- Statistically significant PTSD symptoms in fathers of NICU babies (Binder, et al., 2011)
- If one partner is experiencing PTSD symptoms, there is an increased likelihood over time that the other partner will also experience increased symptoms of PTSD (Binder, et al., 2011)
General population risk factors for developing postpartum mental health difficulties

• A personal or family history of depression, anxiety, or postpartum depression
• History of premenstrual dysphoric disorder (PMDD or PMS)
• Inadequate support in caring for the baby
• Financial stress
• Marital stress
• Complications in pregnancy, birth or breastfeeding
• A major recent life event: loss, house move, job loss
• Mothers of multiples
• Mothers whose infants are in Neonatal Intensive Care (NICU)
• Mothers who’ve gone through infertility treatments
• Women with a thyroid imbalance
• Women with any form of diabetes (type 1, type 2 or gestational)

(Postpartum Support International, 2017)
NICU specific risk factors for developing postpartum mental health disorders or adjustment difficulties (a sampling)

- Separation from child (Wigert et al., 2006)
- Severity of infant health issues (Franck et al., 2005), exacerbated by appearance of ill baby (Joseph et al., 2007; Miles & Holditch-Davis, 1997)
- Lower maternal visitation rates (Greene et al., 2015; Franck et al., 2005)
- Longer hospital stays (Erdem et al., 2010)
- Feeling excluded from, uninformed about, or incompetent in child’s care (Wigert et al., 2006)
- Separation, or lack of involvement, from partner (Hagen et al., 2016)
- Difficulty establishing attachment or bonding with infant (Hofer, 1995; Feldman et al., 2003)
- Feelings of loss of control (Whitfield, 2003)
- Perception of high risk/high stress regardless of objective risk (Binder, et al., 2011)
- Early parental PTSD symptoms predictive of later difficulties with sleeping, eating and sensitivity of maternal behaviors (Vanderbilt et al., 2009)
- Difference in developmental outcomes between preterm and full term babies at 18 months correlated to mother’s mental health and not to perinatal risk factors (Binder, et al., 2011)
- Difficulty or reluctances to access mental health services or support resources due to desire to stay with baby in the hospital (Poel, Swinkels, & DeVries, 2009)
Premature birth has been associated with a number of adverse maternal psychological outcomes that include depression, anxiety, and trauma as well as adverse effects on maternal coping ability and parenting style. Infants and children who were premature are more likely to have poorer cognitive and developmental functioning and, thus, may be harder to parent” (Brecht et al., 2012)
The NICU Experience
NICU Nurses Experience
The Good

◦ Working with babies and their families
◦ Learning something new
◦ Sending babies home
◦ Great colleagues
The Challenging

- Constant change
- Unpredictable
- At any moment you have to be ready to go!
- Consistency and/or interpretation of the rules
- Complexity
What do we do now?

Just do something!

Family Centered Care
Fairview’s Nursing Professional Practice Model

**Nursing is Partnership-Based Healthcare**
- Being Present
  - Relationships
    - Mutual Respect
    - Communication
- Values
  - Dignity, Integrity, Service, Compassion, Innovation
- Care Delivery
  - Connection to Story
  - Compassionate
- Shared Decision Making
  - Evidence-Based Practice
  - Being Heard
- Recognition
  - Acknowledgement
  - Advancement

**Stories**
- Evidence
  - Relationship-Based
  - Whole Person
  - Self-care
  - Holistic Modalities
  - Wellbeing
  - Nature

**Active Caring**
- Integrative Nursing

**EXPERIENCE • EXCELLENCE • EXCELLENCE**

**WE ARE WE PARTNER WE DO**

**Care Delivery Model**
Core Concepts of Patient- and Family Centered Care

- **Dignity and Respect.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

- **Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.

- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

- **Collaboration.** Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation and evaluation; in research; in facility design; and in professional education, as well as in the delivery of care.

Development of the NICU Parent/Family Advisory Council
The NICU Parent/Family Advisory Council

**Mission**
Our mission is to provide a forum for parents and families of NICU newborns to collaborate, educate and inform health care teams regarding parent and family values and wishes in the preferred care of the newborn.

**Vision**
The NICU Parent and Family Advisory Council will champion collaboration between parents and families of NICU newborns with the healthcare team, in order to evolve together as one team to deliver health care at the highest level of service with compassion, dignity and integrity.
Timeline

**June – August 2015**
- Steering committee is created
- Literature review is conducted
- Connections made with several hospitals that have NICU specific PFAC’s
- Develop a rough draft of the councils by-laws, mission and vision (to be edited and approved by the future PFAC)
- Design recruitment materials
- Staff education (NICU)

**September – November 2015**
- Continue staff education
- Send recruitment postcard to NICU families (discharge date of 1/1/14 – 8/31/15)
- Attended FRH NICU Reunion in October for additional recruitment
- Attended the Institute of Patient & Family Centered Care Conference

**December 2015 – January 2016**
- Connect with interested families, 8 moms total
- Conduct phone interviews with 8 interested moms
- Mail volunteer paperwork to interested moms

**February 2016 – Present**
- First meeting, February 16th, 2016
- 10 meetings a year (2016 and 2017)
NICU PFAC Focus Areas

After an extensive brainstorming session in early 2016, four main areas of improvement were decided upon by the Advisors:

° Communication between parents and providers
° More support for parents/caregivers
° Events for current/recent families
° Unit resources
NICU Comfort Plan

Comfort Measures

Our Goal: Our overall goal is to eliminate/minimize actual or potential sources of discomfort during your baby’s NICU stay. We want to partner with you to identify a few techniques to use to provide comfort for your baby. We encourage you to re-visit these measures frequently and update your choices on your baby’s white board as needed.

Daily Comfort
- Sucking (on pacifier or gloved finger)
- Breast feeding
- Breast milk
- Skin-to-skin contact (kangaroo care)
- Swaddling
- Repositioning
- Hand hugs
- Cluster cares (to promote undisturbed rest)
- Warmth
- Rocking
- Physical Therapy
- Other (decrease light, decrease noise, music)

Comfort for Procedures (IV starts, lab draws, neotube placement, etc).
- Oral sucrose (a very sweet tasting sugar liquid that reduces pain)
- Breast milk
- Swaddling
- Warmth
- Other
NICU PFAC Accomplishments

2016 accomplishments:

• An extensive list of ideas, wishes, and areas of improvement for the FRH NICU. This list has been shared with NICU staff and some of the ideas are already put into practice. For example, making sure NICU is discussed on Birthplace tours, letting parents pick out their child’s first outfit and getting staff pictures put up on the unit.

• Collaborate with NICU staff on “NICU Comfort Plan” for newborns

• Attend March of Dimes March for Babies event in April 2016

• Complied suggested book/resource list for family members of NICU patients

• Meeting with NICU Medical Director and Neonatal Nurse Practitioner to discuss parent/provider communication

• Meeting with Chaplain Resident, to discuss improving support for parents/caregivers

• Meeting with NICU Lactation Consultant, to discuss supporting parents through feeding concerns

• September Pizza Party for current NICU families

• Helped plan and attended the Fall 2016 NICU reunion

• Received a $1,000 grant to purchase a “NICU Resource Library” from the Fairview Foundation Women’s Giving Circle

• Gave NICU staff a “Mani Thanks” appreciation gift at Thanksgiving

• Developed marketing to create a NICU PFAC pamphlet that all NICU families will receive

• Evaluated FRH Policies regarding hand hygiene and children as visitors

• Nurse/staff photos added to unit

• Recruited 6 new members
NICU PFAC Accomplishments

2017 accomplishments & goals (so far)

- Additional brainstorming and adding to the list of ideas, wishes and areas of improvement
- Book cart set up and “NICU Resource Library” added to unit
- Development of subcommittees including:
  - Sibling/family resources
  - Discharge resources
  - Parent to Parent mentoring program
  - Communication
- Development and pilot testing of a Parent to Parent program
- Development of discharge planning tool for families
- Regular NICU events (i.e. pizza nights)
- More video conferencing carts purchased
STEPS TO HOME

My Basic Care:
- Temp's Dude
- Bulb Syringe
- Bath - Sponge
- Tummy Time
- Blanket
- Dressing

Feeding Me:
- Infusion Feeding
- NG Tube Feeding
- Donor Milk & Gent
- Breast Feeding
- Bottle Feed

Comforting Me:
- Hand Hold
- Skin to Skin
- Cuddle
- Calm & Soothe

Taking Me Home:
- Blanket
- Bibs
- Sippy Cup
- Toys
- Stretchy Band
- Blankets
- Equipment
- Pacifier
- Laundry Bag
## NICU PFAC and Reducing Risk Factors

### Risk Factor

- Separation from child (Wigert et al., 2006); Difficulty establishing attachment or bonding with infant (Hofer 1995; Feldman et al., 2003)

- Feeling excluded from, uninformed about, or incompetent in child’s care (Wigert et al., 2006); Feelings of loss of control (Whitfield, 2003); Perception of high risk/high stress regardless of objective risk (Binder, et al., 2011)

- Difficulty or reluctance to access mental health services or support resources due to desire to stay with baby in the hospital (Poel, Swinkels, & DeVries, 2009)

### NICU PFAC Initiative

- Video conferencing; family friendly environment (i.e. NICU Resource Library, family lounge, sibling resources); milestone cards; photo book; choosing child’s first outfit; daily update emails; parent participation in baby daily care

- Comfort plan; “Steps to home;” daily update emails; meeting with doctors, nurses, lactation specialist to improve communication and consistency; photo wall; parent involvement in daily care routine; information provided prior to, and at regular intervals, throughout NICU stay; incorporation into Skills Day

- Development of supportive community: NICU family events, P2P program, NICU reunion; NICU Resource Library (including mental health books); mental health resources in information folders; better use of Chaplain services
Questions related to NICU PFAC initiatives include:

1) During this hospital stay, how often did providers keep you informed about what was being done for your child?

2) How often was there good communication between the different doctors and nurses?

3) Hospitals can have things like toys, books, mobiles, and games for children from newborns to teenagers. During this hospital stay, did the hospital have things available for your child that was right for your child’s age?

4) During this hospital stay, how often did your child’s doctor explain things to you in a way that was easy for you to understand?

5) How often were you able to discuss your worries or concerns with a doctor?

6) During this hospital stay, how often did your child’s nurses explain things to you in a way that was easy for you to understand?

7) How often were you able to discuss your worries or concerns with a nurse?
Patient Experience Survey Results 2016

* Patient experience survey sent to all patients discharged from FRH NICU; Response rate: 2016 = 24%; Questions on a Likert scale
Patient Experience Survey Results 2017 YTD

Fairview Ridges Hospital NICU Patient Experience Survey

- Nurses concerns (7): 98 (2016) vs 100 (2017)
What’s Next?
Questions or Comments?

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