When A Hospital Becomes Home: Implementing Home Visiting within NICU settings
A little about myself…

• Peggy MacLean, Ph.D., IMH-III
  • Clinical Psychologist with specialty in early childhood mental health
  • Clinical and research focus has been on the impact of trauma on parents and infant
    • How do parents perceive their child after a NICU hospitalization?
    • How does a difficult birth and a NICU experience impact parents?
  • Director of the UNM HATCH Program, a home visiting program providing services during and after to families experiencing a NICU hospitalization

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Overview of Presentation

• Trauma-informed understanding of the NICU experience
  • Family’s experience
  • Child’s experience
  • Staff’s experience

• UNM HATCH Program
  • Services provided
  • Lessons Learned
September is
#NICUAwarenessMonth

National Perinatal Association
NICU AWARENESS MONTH
nationalperinatal.org/NICU_Awareness

It's not just preemies
More than half of all babies admitted to the NICU are full-term infants with special medical needs.

Educate. Advocate. Integrate.
“A NICU is akin to a trauma center for all participants. Fragile babies struggle to survive and grow. Parents worry constantly while trying to maintain optimism and hope. Staff attempt to avoid burnout while both encouraging distraught parents and acknowledging the times of poor prognosis. Distress is the companion of everyone.”

MT Hyman and St.Hall
Distress is the companion of everyone....
The Family’s Experience

Expected

Reality
Stressors in the NICU

• Fear for baby’s survival & future
  • Will s/he be okay?
• Medical complexities & uncertainties
  • What is happening?
Stressors in the NICU

• Distress around baby’s appearance & behavior

• Disruption in parental role
  • Will I be able to care for my baby?
  • Am I the parent?
Stressors in the NICU

- Lack of social support/ sense of isolation
  - Distance
  - Lack of understanding
  - Potential blame for infant’s condition

- Violated expectations
  - Grieving the “wished for” baby
  - Coping with unexpected labor & delivery
Stressors in the NICU

• Family concerns
  • Caring for older child(ren)
  • Dedicating time with baby in the NICU

• Financial concerns
  • Associated medical cost
  • Childcare cost
  • Employment concerns
Stressors in the NICU

• Difficulty navigating NICU environment
  • Challenging interactions with medical staff
• Multiple rotating providers
• Lack of privacy
Understanding Parental Mental Health

• **Pace et al., 2006**
  - Explore % of parents who had depression and anxiety scores above clinical cut-off during and after NICU hospitalization

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**During NICU**

- **Mothers:**
  - 40% depression
  - 48% anxiety

- **Fathers:**
  - 36% depression
  - 37% anxiety

**6 months following birth**

- **Mothers:**
  - 14% depression
  - 25% anxiety

- **Fathers:**
  - 19% depression
  - 20% anxiety
Understanding Parental Mental Health

- Lefkowitz, Baxt, & Evans, 2010

**Acute Stress Disorder**
3-5 days post-NICU admission
- Mothers: 35%
- Fathers: 24%

**PTSD**
30 days post-NCU admission
- Mothers: 15%
- Fathers: 8%
The Presence of Pre-Existing Stressors

• Families of low socioeconomic status (SES) and of minority race or ethnicity status
  • Are overrepresented in the NICU (MacDorman, 2011)
  • Have higher rates of readmission (Brooks-Ginn, McCormick, & McCarton, 1998)
  • Are disproportionately burdened by the out-of-pocket costs (McCormick, Bernbaum, Eisenberg et al., 1991)
The Presence of Pre-Existing Stressors

Racism has been associated with higher likelihood of preterm birth (Bower, Geller, Perrin et al., 2018)

- Racism can lead to
  - a physiologic response resulting in overactivation of the hypothalamic–pituitary–adrenal axis and release of cortisol and other stress hormones,
  - unhealthy coping mechanisms such as substance use and overeating,
  - differential exposure to social and environmental risks
  - differential quality of care within the health care system

  Williams & Mohammed, 2013
The Presence of Pre-Existing Stressors

• Alhusen, Lucea, Bullock, et al., 2013

Women experiencing intimate partner violence (IPV) had a higher prevalence of substance use than their non-abused counterparts.

Women experiencing IPV was associated with a fourfold increase in having a Small for Gestational Age neonate.

Women who reported substance use had five times the odds of having a neonate classified as SGA or Low Birth Weight.
The Presence of Pre-Existing Stressors

• Approximately 25-50% of infants have Neonatal Abstinence Syndrome/Neonatal Opiate Withdrawal Syndrome

• In NM, NAS rate increased by 324% between 2008 and 2017 (Garcia Saavedra, 2018)

• Rates of prenatal exposure without NAS are higher
The Presence of Pre-Existing Stressors

- **Torchalla et al. 2017**
- Explored trauma in pregnant and newly parenting women with substance use disorder

<table>
<thead>
<tr>
<th>Trauma in Childhood</th>
<th>Continued Trauma in Adulthood</th>
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<tbody>
<tr>
<td>• All women reported childhood maltreatment</td>
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<td>• 77% reported sexual abuse alongside other forms of abuse/neglect</td>
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<td>• 87% reported emotional abuse</td>
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<td>• 74.2% reported physical abuse</td>
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<tr>
<td>• 51.6% reported sexual abuse</td>
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</table>
Challenges Coming Home

- Concerns around caring for infant’s vulnerabilities
  - Sleep, feeding, & regulation difficulties
- Lingering fears about baby’s survival, health & safety
  - Transitioning from highly monitored NICU to an unmonitored home
- Uncertainty about developmental outcomes
Challenges Coming Home

• Ambivalence about the relationship
  • Loving baby, but not feeling bonded with baby
    • Holding baby outward or at a distance
    • Not making eye contact

• Ongoing experience of loss, grief, guilt, anger, & fear
  • Often without opportunity to process
  • “No one asked me about how I was doing”
Challenges Coming Home

• Sleep deprivation & exhaustion
  • “I’m the only one who can care for this baby”

• Sense of isolation
  • “No one understands”

• Higher rates of conflict
  • with partner
  • with friends and relatives
Challenges Coming Home

• Discharged with a long list of needed programs, specialist appointments, and complex care instructions
  ◦ At a particularly vulnerable time
  ◦ Often without understanding what each referral is for
Challenges Coming Home

• At times, systems of care can be:
  • (At Best) Disjointed
    • Navigating different intakes/timelines
    • Waiting Lists
  • (At Worse) Contentious
    • Perceived competition
  • Confusing
    • How are they similar/different?
  • Unsafe
    • Longing for privacy
    • Will it increase my risk of Child Protective Services involvement?
    • Will it highlight my immigration status?
Challenges Coming Home

Financial stressors
- Leave timelines
- Fear of losing employment
- Difficulties obtaining short and long-term disability
- Medical bills

Navigating possible return to work
- Difficulties finding appropriate child care
Different Experiences
Challenges Coming Home

Pre-existing stressors often exacerbate

- Transportation and housing concerns
- Poverty
- Substance use difficulties
- Domestic violence
- Pre-existing mental health difficulties
- Language barriers
- Immigration status
- Lack of support
Understating the Child’s Experience

Table 2. Painful Procedures Commonly Performed in the Neonatal Intensive Care Unit

<table>
<thead>
<tr>
<th>Diagnostic</th>
<th>Arterial puncture</th>
<th>Bronchoscopy</th>
<th>Endoscopy</th>
<th>Heal lancing</th>
<th>Lumbar puncture</th>
<th>Retinopathy of prematurity examination</th>
<th>Suprapubic bladder tap</th>
<th>Ventriculostomy</th>
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<tr>
<td>Therapeutic</td>
<td>Bladder catheterization</td>
<td>Central line insertion/removal</td>
<td>Chest tube insertion/removal</td>
<td>Chest physiotherapy</td>
<td>Dressing change</td>
<td>Gauging tube insertion</td>
<td>Intramuscular injection</td>
<td>Peripheral venous catheterization</td>
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</table>

tests | procedures

- poking/IVs and injections
- NPO
- infusion
- blood support
- dressing change
- surgery
- biopsy
- tube placement
- inpatient admission days
- isolation
- IV antibiotics
- line/port PICC
- clinic/home health visit
- radiation
- ER ambulance
- respiratory support
- isolation
- IV antibiotics
- line/port PICC

NMM
Understating the Child’s Experience

• Newnham, Inder, & Milgrom, 2009
  • NICU Physicians and nurses rate the perceived stress severity of acute events and chronic living conditions of infants in the NICU.
  • Nearly all events and conditions were perceived to be stressful to infants.

Follow-Up Engagement

• Medically at-risk infants have lower rates of home visiting engagement (Alonso-Marsden, Dodge, O’Donnell, et al., 2013)

• Risk of child maltreatment is higher among NICU graduate, especially during the first year of the infant’s life and among families with multiple risk factors (Risch, Owora, Nandyal et al., 2014)
HATCH Program: Helping All To Come Home

- Initial collaboration between CYFD Home Visiting, UNM NICU, and Center for Development & Disability

- Provides support to parents during & after their child’s NICU hospitalization

- Help increase access to & use of community resources

- Provide training to NICU-related & early childhood professionals around working with high risk infants and families

- Flexible duration depending on family need
  - Approximately 3 months with most, up to 6 months with some
Our “Hatching” process

- Concerns were voiced around the increase in infant safety concerns seen in the NICU and limited resources available

- Concerns centered on:
  - The need to increase support to high risk families at birth to prevent poor outcomes
    - High rates of prenatal exposure, NAS, undocumented status, IPV
  - Follow up engagement with referred services
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<tr>
<th>April 2016-December 2017</th>
<th>January-December 2018</th>
<th>January-December 2019</th>
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</table>
| Developing relationship w/ UNM NICU  
- Initial wariness | January 2018-began serving UNM families | February 2019-½ Day Awareness Training to Presbyterian 1st cohort |
| Spring 2016-Fall 2017- monthly planning meetings w/ UNM NICU Leadership | January-July 2018-began meeting with Presbyterian NICU | Summer 2019-began meeting with Lovelace NICU |
| Fall 2017- UNM NICU FAN Awareness Training w/ nurses | July 2018-FAN Awareness Training w/ Presbyterian NICU staff | Begin receiving referrals from Lovelace NICU |
| December 2017- 1-Day FAN L1 Training with UNM Developmental Care, NICU social workers, & any nurse interested in attending | September 2018- began receiving referrals from Presbyterian NICU | Expand from metro to outside counties |
|                         | September 2018- ½ Day Awareness Training to UNM Lactation nurses |
Facilitating Attuned INteractions

• FAN Approach
  • Dr. Linda Gilkerson at Erickson Institute
  • A conceptual model and practical tool for family engagement and reflective practice that focuses on:
    • Recognizing parent cues and responding based on these cues
    • Recognizing one’s own regulation and its impact
Levels of FAN infusion

• With families
• With HATCH home visitors (reflective supervision)
• With NICU staff
  • Developmental Care therapists
  • NICU social workers
  • NICU nurses
Emotional support: Being *With the many emotions* ....

- Prior to discharge, the “work” is often around listening to their experience and the overwhelming feelings associated with their baby’s birth & hospitalization

  - Listening to the fear & worry
    - Will he/she be okay? What does this mean for the future?

  - Listening to the pain & frustration
    - Why is this happening?
    - Frustration with staff, family, ....

  - Celebrating joyful moments
    - NICUs can be lonely, little victories are important...
Emotional support: Being With the many emotions ...

• Listening to the mixed emotions associated with coming home
  • Relief
  • Excitement
  • Fear/ worry
  • Exhaustion

• Supporting them around the many emotions associated with what comes next
  • The concern around work & childcare
  • Worry about siblings & their experience
  • Worry around germs & protecting their baby
Parenting support: Exploring together

• Learning who is this little baby?
  • Observing & reading their baby’s cues

• Learning their likes & dislikes
  • He/she likes it when I do ….  
  • He/she does not like when I do….

• Exploring what they feel more & less confident in
  • Karitane Parenting Confidence Scale

• Exploring what they have noticed, tried, & discovered about their baby
Explore Together: Neonatal Behavioral Observation scale

• Neonatal Behavioral Observation:
  • Relationship-building tool that helps caregiver’s understand their baby’s language
  
  • Focuses on what makes this baby unique and different
  
  • Helps us remember that ALL babies are born with a rich vocabulary
    • Body movements & postures
    • Cries & sounds
    • Visual responses
    • Self-regulatory strategies

• With babies with special need, the focus is often on what the baby isn’t doing
Parenting Support: Supporting the DO-ing

• Supporting the parents in being the expert for their baby
  • Many parents do not experience this…

• Noticing & acknowledging the bond between baby & parent is powerful
  • Parents of vulnerable babies often worry about the bond with their baby & their role
  • Acknowledge Angel Moments (FAN)
Parenting Support: Supporting the DO-ing

- Home visitors are trained in infant massage & obtain support from an occupational therapist around teaching parent simple & safe ways on massaging their baby
  - Providing safe, healing touch

- Provides parents with a way of connecting with their baby and a sense of confidence around touch
Parenting Support: *Supporting the DO-ing*

• Supporting families around difficulties that arise
  • Getting their home ready for discharge
  • Medicaid & insurance
  • Transportation
  • DD & SSI application

• Help navigating/understanding systems
• Help navigate differing/overwhelming recommendations
  • Attending medical visits, if needed
  • Helping them prepare questions for upcoming medical visits
“Staff attempt to avoid burnout while both encouraging distraught parents and acknowledging the times of poor prognosis. Distress is the companion of everyone.”
Staff Stressors in the NICU

- Frequent and unpredictable medical crises
- Conflicts with distressed families
- Sensory stimulation
  - Deficient/unnatural lighting, excessive noise
- Long hours
  - Workload, staffing
- Lack of privacy throughout the day
- Rotating staff, including neonatologists
  - Associated changing expectations

Hall et al., 2015
Staff Stressors in the NICU

• Emotional experience of caring for vulnerable infants
  • Will this baby survive?
    • Balancing hope with risk
  • Will this baby be okay?
    • Limited follow-up
  • Will this parent be okay?
Understanding the Provider’s Experience

• Tatano Beck, Cusson, & Gable, 2017

• 175 NICU nurses completed the Secondary Traumatic Stress Scale & interviews around traumatic experiences caring for critically ill infants

• 49% had scores that indicated moderate to severe secondary traumatic stress
FAN can provide some support to nurses...

- NICU nurses have their own **urgent concerns**
  - Worry for the babies & parents
  - Feelings of helplessness in high risk situations
  - Worry around the safety & well-being after discharge
  - Frustration & helplessness around lack of support & services
  - Anger around parental behaviors & impact
  - Sadness around infant outcomes & family circumstances
FAN can provide some support to nurses…

• “Stop being a baby, baby”

• “I don’t care if she is a crack-***, she needs to come visit her baby”

• “I’m the medical professional, and I am telling you …”

• “Give him to me, I will have to feed him”

• Similar to parents, without awareness & support, their urgent concern can led to maladaptive responses
Influencing NICU environments: FAN Trainings

• FAN General Awareness Training
  • Fall 2017-UNM NICU nurses
  • Summer 2018-Presbyterian NICU nurses

• Half-Day Abbreviated FAN Training
  • UNM Developmental Care & any interested NICU staff (nurses, neonatologist)
  • Fall 2018- UNM NICU lactation nurses
  • December 2018- Presbyterian Withdrawing NICU Team

• Annual Amazing NICU Conference
  • Engaging NICU families using the FAN
Lessons learned along the way…

- Developing relationships with NICUs is key
  - Approaching each NICU as a different culture
  - Try to understand NICU needs and be responsive to them
  - Remember that you are a “guest”

“Nothing …is worth having or worth doing unless it means effort, pain, difficulty…” Theodore Roosevelt
Lessons learned along the way…

• Be prepared for setbacks
  • Taking a trauma-informed approach means understanding trauma-related behaviors
  • High turn over rates in NICU is challenging
    • Since January 2018, one NICU had all three NICU social workers leave

• Be open to changing course
  • Changing the referral process based on our observation
  • Approaching referrals differently in different hospitals
Lessons learned along the way…

• Support staff around the emotions that come up
  • Working with fragile babies & parents brings up a lot in the home visitors

• Adopt a trauma-informed lens towards working with parents, home visitors, and NICU staff

• Prepare home visitors for the possibility of having one of their babies pass away
Notice small victories

• Similar to what we tell parents, we need to remember to notice the small victories
  • Appreciations from families served
  • Requests for FAN training by NICU staff
  • A nurse & attending physician making a referral
  • A home visitor reaching a full caseload
It takes a village...

• Monica Armas Aragon, LCSW (Developmental Care Director)
• Marcia Morirata, Psy.D., UNM CDD Director
• Janelle Fuller, MD (Chief, Division of Neonatology)
• Denise Pacheco (HATCH home visitor)
• Jennifer Barol, LCSW (former HATCH home visitor)
• Claudia Hornbeck, LCSW (former HATCH home visitor)
• Kristina Blakney (HATCH Program Coordinator)
• Karen Longnecker (HATCH home visitor)
• Alejandra Rebolledo Rea (Division Director, CYFD Early Childhood Services)
• Katrina Montano-White (Bureau Chief, CYFD Early Childhood Services)
• Rhonda Montoya (NM Home Visiting Supervisor)
• Jena Masland, OT (Presbyterian Withdrawing Team)

• Una Vicenti, OTL/R (Infant Massage Support)
• Catherine Simpson (UNM NICU social worker)
• Dalia Medina-Bustillos (UNM NICU social worker)
• Kristine A Richardson (Lovelace NICU)
• Marianne Wood (Lovelace NICU)
• Jaci Imberger, RN (FAN co-trainer)
• Rachael Cervantes & Trudi Murch, Smooth Way Home, Southwest Human Development
• Sherryl Scott Heller, PHD, T-BEARS
• Peggy Kaufman & Wendy Hurwitz, LMHC; Fragile Beginnings,
• Center for Early Relationship Support
Thank you

My feet are very small
and the way is hard
but I do not walk alone

NICU Baby
Questions, thoughts, & comments


