Caring for Parents, Caring for Ourselves

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Disclosures

• I am a paid consultant for The Wellness Network and Chief Medical Advisor for the parent education video series *Your NICU Baby.*
Goals of My Presentation:

1. Understand the rationale and importance of providing psychosocial support to NICU parents.

2. Learn the components of a comprehensive NICU family support program.

3. Learn why provision of emotional support to NICU staff is critically important, and how this can be accomplished.
What are NICU parents feeling?

- Shock
- Fear
- Guilt
- Anger
- Lack of control
- Pain
- Jealousy
Psychological Distress

• Increased occurrence in:
  – Parents of high-risk infants (defined as having BPD).
  – Those whose infants/children had higher levels of medical risk.

• Result: Parents experience difficulty concentrating and making decisions.

Parental Depression

• 60% of preemie parents were at risk for depression during NICU, and 20% at risk even up to 2 yrs. after delivery.
  – High risk if baby is medically fragile.
  – Greatest risk if baby requires rehospitalization.

• Depressed moms show fewer attachment behaviors; infants respond less to these moms.
  --Callahan, 2002; Callahan, 2006; Cho, 2008; DeMier, 1996; Huhtala, 2012; Miles, 2007.
PTSD in NICU Parents

• More common in NICU parents than in mothers of term infants.
• Symptoms related to:
  • Infant’s birthweight
  • Infant’s GA
  • Severity of medical complications
  • Length of infant’s hospitalization
  • Mother’s age
  • Cesarean delivery

--Callahan, 2002; Callahan, 2006; DeMier, 1996.
Factors Disruptive to Bonding in the NICU

• Maternal and paternal separation.
• Too much light and noise.
• Too little tactile and vestibular stimulation.
• Disruption in sleep.
• Effects of acute and chronic illness.
• Lack of privacy.
Fear that Baby may die...

...can lead to attachment problems between either parent and baby, even when there is no direct threat to the life of baby.

• How will this baby turn into this toddler?
Biology of Attachment

Babies are capable of expressing a behavioral repertoire in relation to the capacity of their internal brain activity; this stimulates the reciprocal relation with corresponding brain activity of the caregivers.
“In preterm babies, the behavioral repertoire is much less developed because of immaturity of their brains; therefore they are not yet fully equipped to enter the dialogue with their caregivers.”

Mothers of Preemies

• Often have trouble interpreting their baby’s behavior:
  – Have difficulty decoding baby’s cry: Pain, hunger or anger?
  – Don’t recognize or misinterpret signs of infant distress or “shut down.”
  – Get fewer cues from baby: less eye contact, fewer smiles.
Parenting Preemies

• Parents lose confidence in their parenting skills.
• They perceive their infants as “difficult.”
• The higher moms’ depressive symptoms are, the less infants respond to mothers during feeding interactions.

--Cho, JOGNN, 2008
Maternal depression has a negative relationship with child's physical growth, as well as with cognitive and developmental outcomes.

--Surkan, 2012; Bernard-Bonnin, 2004
The Vicious Cycle

1. Sick, VLBW baby
2. Parental distress, depression
3. Impaired bonding with baby
4. Worse developmental outcome of child
5. Parent becomes more depressed

--Huhtala, *Peds*, 2012
Bottom Line

• The goal of providing adequate psychosocial support to NICU parents is to enable them to **build strong families**.

• We can help parents minimize or avoid the adverse psychological impact of the NICU experience and bond with their babies, both of which will promote optimal development of their child.
Role of Mental Health Professionals:
Recommendations of NPA

1. All NICUs with ≥20 beds should have an MSW social worker and PhD psychologist on staff, with roles overlapping re counseling, screening, educating staff and teaching parenting skills.

2. NICU parents should be screened for emotional distress within 48 hrs. of admission and within 48 hrs. prior to discharge (for stays > 1 wk).

3. Layered levels of emotional support should be available to all parents.
Layered Levels of Emotional Support

Stepped Care Pyramid (Kazak, 2006)

Clinical/Treatment
- Persistent and/or escalating distress
- High risk factors

Targeted
- Acute distress
- Risk factors present

Universal
- Children and families are distressed but resilient

Consult behavioral health specialist
Provide intervention and services specific to symptoms. Monitor distress.
Provide general support – help family help themselves. Provide information and support. Screen for indicators of higher risk.
Role of Peer-to-Peer and Family Support
Parents’ Own Support Networks

• May actually increase parents’ stress because of lack of understanding of the NICU experience.
• May not be available due to geographic distance and other commitments.
• Family and friends may be grieving, which contributes to parents’ distress.
Interaction with Services from HCP

• Not all NICUs provide formal support; not all have social workers.

• Peer-to-peer help should not replace professional help or services provided by HCP.

• Peer-to-peer support should be an integral component of family-centered care.
Recommended by AAP

• “Pediatricians should encourage and facilitate peer-to-peer support and networking, particularly with children and families of similar cultural and linguistic backgrounds or with the same type of medical condition.”

  --Patient- and Family-Centered Care and the Pediatrician's Role, *Peds*, 2012
# Effects of Peer Support on Parents

<table>
<thead>
<tr>
<th>Increases</th>
<th>Decreases</th>
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<tbody>
<tr>
<td>Confidence, self-esteem, well-being</td>
<td>Stress</td>
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<tr>
<td>Perception of social support</td>
<td>Anxiety</td>
</tr>
<tr>
<td>Problem-solving capacity and adaptive coping, including acceptance</td>
<td>Depression</td>
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<td>of situation</td>
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<tr>
<td>Mental health</td>
<td>Isolation</td>
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<tr>
<td>Sense of optimism and hope; sense of empowerment</td>
<td>Physical illness</td>
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<tr>
<td>Visiting at hospital, interacting with their baby</td>
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Models of Peer-to-Peer Support

- Individual support in person
- Support by phone
- Parent support groups
- Internet support
- March of Dimes Family Support specialists
- Sibling education or play groups
Barriers to Parents’ Accessing Support

• Not every NICU has type of support that would best help each parent.
• Not every parent program has ability to match mentor parents on all dimensions.
• Programs are harder to implement in smaller NICUs.
• Parents may not be aware of programs.
• Parents may not feel a need for support until they’ve been in the NICU a long while.
More Barriers

• Parents may not want to leave baby’s bedside or to leave home to access support.
• Outreach may be required, especially to culturally diverse families, in different languages.
• Parents who are not parents of preemies may feel they don’t fit in, services not available for them.
• Cost, institutional acceptance, space.
Peer-to-Peer/Family Support: Recommendations from NPA

1- Every parent should be offered peer support.

2- In-person support is a best practice.

3- Consistent peer support from antepartum period through discharge is desirable.

4- Support should be offered to members of baby’s family including both parents, grandparents, and siblings as needed and desired.
Recommendations from NPA for Staff Education

1. All staff should receive training simultaneously.

2. Content:
   a. Normal/expected parental responses to NICU.
   b. Communication skills, including active listening and how to give “bad news.”
   c. Methods of providing support to families.
   d. Cultural competence.
   e. Elements of self-care for staff.
3. Methods of training:
   a. Simulation training.
   b. Other: self-study modules, web-based training, didactic presentations, outside speakers, etc.

4. Ongoing education should be fully integrated into other platforms.

5. Administrative support for staff education is critical.
NICU Parents’ Needs

- To watch over/protect infant.
- Contact with infant.
- Accurate information, inclusion in infant’s care, and to be involved in decision-making.
- To be positively perceived by nursing staff.
- Therapeutic relationship with nursing staff.
- Individualized care.

--Cleveland, Parenting in the NICU, JOGNN, 2008.
To Meet Needs, RNs Provide...

1. Emotional support (including information sharing).
2. Parent empowerment.
3. Welcoming environment with supportive unit policies.
4. Parent education with opportunity to practice new skills.

--Cleveland, JOGNN, 2008
How to deliver “bad news”

• Inform parents of diagnosis within 24-48 hours, plan more intensive conversation at a later time.
• Meet privately with plenty of time.
• Who should present the news?
• Who should receive the news?
• Use a translator if needed and be culturally sensitive.
Delivering “bad news”

- “Ask, tell, ask.”
- When giving bad news, start with positives.
- Be honest, but not brutal. Provide a range of outcomes; discuss uncertainties.
- Listen to parents; give them time to absorb; gauge their response.
- Acknowledge their feelings.
Delivering “bad news”

• Don’t resent parents’ questions or requests for more information.
• Discuss what hope remains.
• Summarize your meeting.
• Provide resources.
• Give parents time alone afterwards.

Caring for Ourselves

SHARE DREAMS, INSPIRE LOVE, HEAL HEARTS, EMBRACE SPIRITS, NURTURE SOULS...

Attribution: ernursescare.blogspot.com
Burnout

• A “state of physical, emotional and mental exhaustion caused by long-term involvement in emotionally demanding situations.” (Pines & Aronson, 1988)
Adverse Effects of Burnout on Patients

- Increases healthcare-associated infections. (Cimiotti, 2012)
- Decreases nurses’ ability to recognize errors and to report them. (Halbesleben, 2008)
- Increases patient mortality. (Aiken, 2002)
- Leads to worse patient satisfaction. (Leiter, 1998)
Adverse Effects of Burnout on the Organization

• Increases rates of employee tardiness and absenteeism. (Duquette, 1994)
• Increases nursing turnover. (Lake, 1998)
• Ultimately, leads to higher costs to the organization.
Affected Nurses Suffer From:

- Greater difficulties in their personal lives outside of work. (Mealer, 2009)
- Higher rates of psychological and somatic complaints, including sleeplessness, muscle tension, headaches, immune problems, GI and CV problems. (Braithwaite, 2008)
- Higher rates of drug and alcohol abuse. (Duquette, 1994; Parker, 1995; Robinson, 1991)
- Higher rates of compulsive gambling. (Espeland, 2006)
How Widespread is Burnout?

• VERY WIDESPREAD!!

• Among 10,184 nurses, more than 40% had burnout. (Aiken, 2002)

• Among 7,228 physicians, 45.8% showed at least one symptom of burnout. (Shanafelt, 2012)

• Among 820 HCP in 44 NICUs, burnout ranged from 7.5% to 54.4%. (Profit, 2014)
Compassion Fatigue

- Someone who has lost the “ability to nurture.” (Joinson, 1992)
- Results from the emotionally intense experience of witnessing tragedy within the work setting and empathizing with those involved. (Lombardo, 2011)
- Also described as secondary traumatic stress disorder (STSD), i.e., someone who indirectly experienced the trauma their patients were going through, and wanted to help. (Figley, 1995)
Burnout and Compassion Fatigue

- Those with burnout tend to withdraw from patient interactions and focus on tasks; those with compassion fatigue may “try harder” in spite of emotional exhaustion.
Nurses: Increased Risk for PTSD

• Study of 173 pediatric and NICU nurses found that 82% had at least 1 symptom of PTSD (nightmares, severe anxiety, panic).
• 21% of respondents had positive screens for possible PTSD.
• Nurses who had PTSD and burnout had more trouble in their personal lives: with personal relationships, schoolwork, general satisfaction with life. (Czaja, 2012)
Study of Secondary Traumatic Stress in LDR Nurses

• 464 LDR nurses surveyed. (Beck, *JOGNN*, 2012)
• 63% of nurses experienced some degree of secondary traumatic stress.
• 26% met criteria for PTSD.
• Top 3 symptoms:
  – Thought about work when didn’t want to
  – Had trouble sleeping
  – Were easily annoyed
Themes Identified

- Struggling to maintain professional role with traumatized patients.
- Agonizing over what should have been.
- Considering foregoing career in LDR to survive.
Bottom Line

• If we as healthcare staff are emotionally traumatized as a result of our work, or if we suffer from burnout and/or compassion fatigue, we won’t be emotionally available to support the families we care for.

• We need to develop strategies to minimize or avoid the adverse effects of our work on us! Doing so will ensure we are better helpers.
1. All staff should support all other staff. (‘Appreciate Your NICU Nurse: Letter from a Neonatologist,’ kevinmd.com, 9/7/14).

2. Staff support should be integrated into the everyday operation of the NICU.

3. All staff should be trained in communication skills and maintenance of work-life balance.
Ways Staff can be Supported

4. Provide opportunities for staff to debrief and process emotions after difficult cases.
5. Provide bereavement interventions during and after provision of end-of-life care.
6. Ensure that channels of communication for all HCP to access support from supervisors is clear.
More Ways to Support Staff

7. Implement a no-tolerance policy towards aggressive family members.

8. Ensure an optimal physical environment in which to work.

9. Consider provision of space for employees to rest or take power naps.
10. Hospitals should adhere to best practices in staffing (AWHONN for nursing), provision of breaks and days off, and orientation and mentoring of new nurses.

11. Hospitals should provide support for staff that develop PTSD or other psychological distress.
Summary

• Parents of babies in NICUs experience great distress and require psychosocial support.
• All NICUs should do their utmost to provide parents with comprehensive family support.
• NICU staff should be both educated in providing psychosocial support to parents, and supported in their caregiver roles.
• The end result will be creation of stronger, healthier families.
I believe the children are our future.
Acknowledgments

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