

Bridging the Gap: Interdisciplinary Recommendations for Psychosocial Support of NICU Parents



Sage Nottage Saxton, Psy.D.
Associate Clinical Professor Pediatrics and Neonatology
Oregon Health and Science University

Pec Indman, EdD, MFT
Postpartum Support International
PSI Trainer and Underwater Fish and Critter coordinator

Members from these Organizations

Academy of Neonatal Nursing	National Perinatal Association
Perinatal Section of American Academy of Pediatrics	National Premature Infant Health Coalition
Association of Women's Health, Obstetric and Neonatal Nurses	Nurse Family Partnership
Council of International Neonatal Nurses	Oklahoma Infant Alliance
Healthy Mothers, Healthy Babies	Postpartum Support International
March of Dimes	Preeclampsia Foundation
National Association of Neonatal Nurses	Society of Maternal Fetal Medicine
National Association of Neonatal Therapists	Society of Pediatric Psychology
National Association of Pediatric Nurse Practitioners	Special Care/Special Kids
National Association of Perinatal Social Workers	Transcultural Nursing Association

Components of Comprehensive Family Support in the NICU



National Perinatal Association: *Recommendations for Psychosocial Support of NICU Parents*

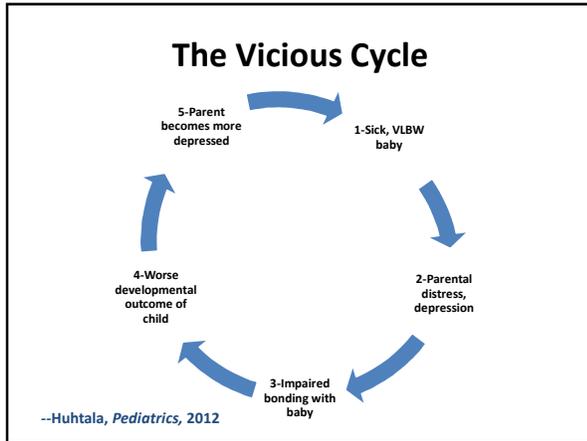
1: The Role of Mental Health Professionals

Rationale and Need

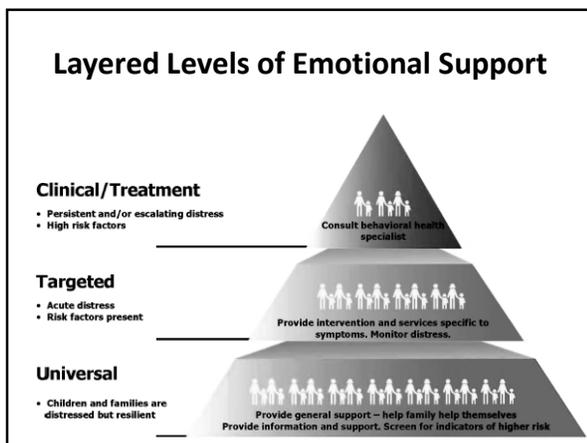
- In the first postpartum year, 20-30% of NICU parents may develop:
 - Depression
 - Anxiety
 - Obsessive-Compulsive Disorders
 - Acute Stress Disorder (ASD)
 - Posttraumatic Stress Disorder (PTSD)
- Other psychosocial stressors include:
 - Financial
 - Family
 - Adjustment Stress

Mothers of Premies

- Often have trouble interpreting their baby's behavior.
- Parents lose confidence in their parenting skills.
- They perceive their baby as "difficult."
- Mothers with more depressive symptoms are less attentive and more restrictive to their babies. --Cho, JOGNN, 2008



- ### Recommendations for the Role of Mental Health Professionals
1. All NICUs with >20 beds should have an MSW social worker and a full- or part-time perinatally trained psychotherapist on staff, with roles overlapping re: counseling, screening, educating staff and teaching parenting skills.
 2. NICU parents should be screened for emotional distress within the first wk after admission and within 48 hrs. prior to discharge (for stays > 1 wk), only if treatment resources are available.
 3. Layered levels of emotional support should be available to all parents.



Preventive Interventions

- Segre, *Journal of Perinatology*, 2013: Listening Visits
- Shaw, *Pediatrics*, 2013: Prevention of Traumatic Stress
- Nearing, *Journal for Maternal-Fetal and Neonatal Medicine: Psychosocial Parental Support Programs*, 2012
- Milgrom, *Pediatric Research*, 2010: Parent Training Study
- Melnyk, *Pediatrics*, 2006: Creating Opportunities for Parent Empowerment program (COPE)

Telemedicine/Web Support

1. Telemedicine can be used for screening and treatment.
2. Telemedicine should follow standards such as those developed by the American Telemedicine Association and American Psychological Association.
3. NICU staff should be familiar with web-based parent support sites.

Antenatal Screening and Support

- When a NICU stay is anticipated, parent support coordinators and MHPs should initiate a relationship before the birth for support and prenatal screening for depression and anxiety in hospitalized mothers.

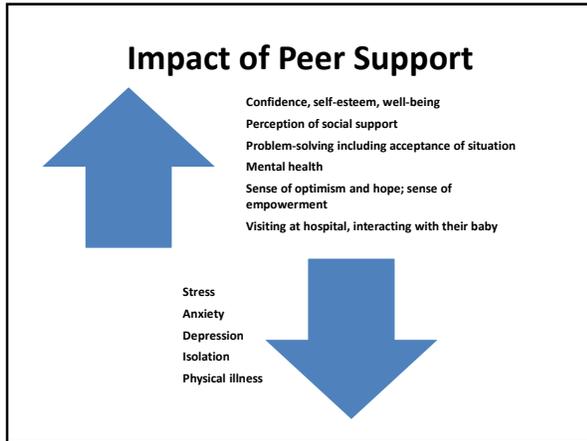
2: Role of Peer-to-Peer and Family Support

Rationale and Need

- Parents' own support networks may 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 also be grieving.

Interaction with Services from HCP

- Not all NICUs provide formal support; not all have social workers.
- Peer-to-peer support should not replace professional help or services provided by Health Care Professionals (HCP).
- "Pediatricians should encourage and facilitate peer-to-peer support and networking" (AAP, 2012).



- ### Models of Peer-to-Peer Support
- Individual in person support
 - Telephone support
 - Parent support groups
 - Web based support
 - Sibling education or play groups

- ### Recommendations for Peer-to-Peer Support
- 1-Every parent should be offered peer support.
 - 2-In-person support is a best practice.
 - 3-Consistent peer support from antepartum period through and beyond discharge is desirable.
 - 4-Support should be offered to members of baby's family including both parents, grandparents, and siblings as needed and desired.

**3: Family-Centered
Developmental Care (FCDC)**

Rationale and Need for FCDC

- Focus is on not just survival but on the quality of baby's life, optimal development, and integration into a healthy family unit.
- Parental involvement lowers parents' stress.
- An interdisciplinary team must be involved.

Recommendations for Family-Centered Developmental Care

1. Family support, including antenatal consultation, should begin whenever maternal or fetal conditions are identified that could lead to a NICU stay.
2. Upon admission to NICU, families receive:
 - a. Culturally appropriate and warm welcome
 - b. Introductory written resources
 - c. Review of NICU routines/equipment (after focusing on baby-parent interaction)
 - d. Assurance of 24/7 information and access to baby

FCDC, con't

- 3. The family is incorporated as collaborative members of the NICU team and taught ways to guide brain development (OT, PT, Speech).
- 4. Staff should receive education on FCDC.
- 5. Staff communication with families should be regular, understandable, personalized, consistent and culturally sensitive.

FCDC, con't

- 6. Policies and procedures should support participation of parents' support system.
- 7. Optimal family support should include provision of these resources: tangible, psychosocial, expanded family, and peer support, and referrals to community services.
- 8. In case of baby's death, palliative and bereavement care services should be provided to family.

FCDC, con't

- 10. Transition to home should begin at baby's admission.
- 11. Quality improvement projects on FCDC should be integral to care provided.
- 12. Hospital committees and NICU policy development should include family advocates as regular members.

4: Palliative and Bereavement Care

Rationale and Need

- Although the APP has outlined practices for palliative care, in some NICUs such care is fragmented or not yet well-defined.
- Decisions to offer palliative care can be ethically challenging and morally distressing, using an interdisciplinary and family-centered team approach can minimize suffering of both babies and their parents.

Rationale and Need

- Palliative care can be a viable alternative to NICU care for:
 - babies born at the edge of viability
 - those diagnosed with life-limiting
 - those who become ill in the NICU and are not responding to aggressive treatment.
- Many HCP feel inadequate in the skills needed to have discussions with families about end-of-life decision-making.

**Parents who lose a baby
should be offered:**

- a. Anticipatory guidance regarding the grieving process;
- b. Participation in bereavement rituals;
- c. Psychosocial supports for all members of the family;
- d. Peer-to-peer support and/or referral to community or internet support organizations;
- e. Counseling re: attempting another pregnancy;

**Parents who lose a baby
should be offered:**

- f. Post-hospital follow-up including:
 - Individual contact by a staff member by phone call or card and again on anniversary
 - Conference 4-6 weeks after death to
 - review autopsy and other results that will help parents understand what happened
 - Provide support and resources as needed

If loss is anticipated:

- 1. An antenatal interdisciplinary conference should be held to:
 - a. Develop a birth, labor, and delivery plan
 - b. Discuss resuscitation vs. a natural death,
 - c. Discuss palliative care options
- 2. Parents should be encouraged to bond and to create memories with their baby during pregnancy.
- 3. Psychosocial support provided for all family members.
- 4. Both practical and psychosocial support provided to help family cope at home if baby survives to discharge.

**5: Post-Discharge Follow-up
and Beyond**

Rationale and Need

- NICU parents' remain at increased risk for PPD and PTSD even after their NICU stay.
- A proactive approach is needed to support the parent-baby relationship during the NICU and after transition to home.
- Studies show a home visiting program may improve outcomes for high risk premature infants. (Goyal, *Pediatrics*, 2013).

**Recommendations for Post-Discharge
Medical Follow-up**

1. Each NICU should have a trained nurse assigned to every family for discharge and transition planning. They should work w/ family to coordinate treatment plans and post-discharge referrals, and ensure family has necessary equipment.
2. While in NICU, families should choose a pediatrician or PCP. The PCP should meet with family before discharge.

Medical Follow-up, con't

- 3. Prior to discharge, PCP should receive telecommunication from doctors already involved in baby's care re medical concerns and parental risk factors. Home visitors should be included in communications.
- 4. All follow-up doctors should have access to a copy of NICU discharge summary containing contact information and dates of appointments with all providers.

Recommendations for Parenting Education

- 1. NICU staff should engage and empower families in developing parenting skills.
- 2. Parents/families should be educated regarding necessary care practices for their baby; parents should demonstrate competence.
- 3. Families should receive anticipatory guidance about psychosocial stresses they may face once baby is home.

Recommendations for Home Visitors

- 1. Home visitation should be provided to all NICU families after they go home.
- 2. After appropriate consents have been obtained, NICU staff and home visitors can share information about the baby's medical status and needs of baby and family.
- 3. Home visitors should be in contact with PCP and other HCP to assure good communication and coordination of care.

Roles of Home Visitors

1. Conduct infant developmental screens.
2. Provide education to parent re: infant health and development and how to provide responsive care to infant.
3. Assess parents' mental health symptoms and determine how these may affect parents' care of baby.
4. Identify and provide resources for family.

Roles of Home Visitors, con't

6. Provide emotional support to families after appropriate training using techniques such as "listening visits."
 - Trained nurses listen to mothers' concerns and do basic problem-solving with them

Recommendations for Post-Discharge Emotional Support

1. A NICU point person should provide PCP and specialists with information re known risk factors for parental emotional distress post-NICU.
2. OB, FP, general Peds, and Peds subspecialty clinics should have staff trained to identify families at risk and to provide supportive services or referrals to them for families in need.

Emotional Support, con't

3. All PCPs caring for mothers and/or babies should have staff with experience in mental health care and psychological screening for stress, depression, and emotional distress.
4. Peer mentors who are involved with families in the NICU should continue these relationships after discharge, if mutually desired .
5. HCP working with post-NICU families should become familiar with internet resources and support organizations for families.

**6: Staff Education:
Supporting Parents**

Rationale and Need

- HCP as well as NICU parents think there is a need for improved NICU staff-parent communication.
- Work in perinatal service areas is stressful; HCP have high rates of burnout, compassion fatigue, and secondary traumatic stress.
- HCP affected by burnout, etc. have reduced ability to provide effective support to parents.

Recommendations for Staff Education

1. All staff should receive training simultaneously on the following:
 - a. Normal/expected parental responses to NICU.
 - b. Perinatal mood and anxiety disorders.
 - b. Communication skills, including active listening and how to give "bad news."
 - c. Methods of:
 - 1) providing support to families
 - 2) improving family-centered developmental care
 - 3) providing culturally effective care.
 - d. Elements of self-care for staff.

Staff Education, Con't

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.

Recommendations for Staff Support

1. Staff should support one another and respect each discipline's contribution.
2. Staff support should be integrated into the everyday operation of the NICU.
3. All staff should be trained in self-care including management of work stresses, maintenance of work-life balance, and management of life skills.



In Summary

- Parents of babies in NICUs may experience great distress and require psychosocial support.
- All NICUs should do their best 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.

In a perfect world...



We would do all of these things to support our NICU families.

Start where you are, because...



Endorsing Organizations*

<p><u>Professional Organizations</u></p> <ul style="list-style-type: none">• Nat Assoc Neonatal Nurses• Nat Assoc Perinatal SW• Nat Assoc Pediatric NPs• Nat Assoc Neonatal Therapists• Academy of Neonatal Nursing• Council of International Neonatal Nurses• Nurse Family Partnership• Marcé Society for Perinatal Mental Health• National Perinatal Association• Postpartum Support International	<p><u>Parent Support Organizations</u></p> <ul style="list-style-type: none">• Canadian Foundation for Premature Babies• European Foundation for the Care of Newborn Infants• Hope for HIE• Tiny Miracles Foundation• NICU Helping Hands• Preeclampsia Foundation
---	--

*As of August 1, 2015

Participating Parent Support Organizations

- Eden's Garden
- Graham's Foundation
- Hand to Hold
- NICU Helping Hands
- Neonatal Intensive Care Unit Parent Support at Mercy Hospital in St. Louis
- Premie Parent Alliance
- Zoe Rose Memorial Foundation

Corporate and Foundation Sponsors



Your NICU Baby
from The Newborn Channel



The Rosemary Kennedy Trust



Prolacta
BIOSCIENCE
Advancing the Science of Human Milk



Loma Linda University



- Full Journal of Perinatology Issue can be found here:
 - <http://www.nature.com/jp/journal/v35/n1s/index.html#rv>
- Workgroups' Comprehensive Support Website:
 - <http://support4nicuparents.org/>

Acknowledgments

Thanks to the following for sharing their photos: the Adams, Decker, du Toit, Gramkow, McFarland, and Saleutogi families.
