Traumatic Stress in the NICU: Implications for Families and Providers

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Session Summary
The focus of this discussion will be on the potential bidirectional influence of the NICU on parents’ psychological functioning and traumatic stress. Clinical information will be provided about stress response, post-traumatic stress, and mood disorders. This talk will also highlight the importance of providing psychosocial support for families, as well as attending to the impact on staff, to help build culture of resiliency.

Session Objectives
Upon completion of this presentation, the participant will be able to:

- review diagnostic criteria for acute stress disorder and post-traumatic stress disorder;
- explore potential etiology and maintenance factors of family and staff stress in the NICU setting;
- introduce recently developed guidelines for staff support and psychosocial care of families in the NICU courtesy of NPA working group.

References
American Psychiatric Association (2015). Diagnostic and statistical manual of mental disorders (5th ed.).
Washington, DC: Author.


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Amy Baughcum, PhD

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“'A NICU is akin to a trauma center for all participants. Fragile babies struggle to survive and grow. Parents and families 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 Hynan and SL Hall,

Overview

• How do we define traumatic stress?
• What makes the NICU experience potentially traumatic?
• How can we tell when a family is at-risk?
• What can we do to help?
• As providers, how can we best take care of ourselves?

NICU parents may feel:
happy
proud
angry
scared
confused
frustrated
lonely
sad
anxious
hopeful
hopeless

General Adaptation Syndrome

• Alarm & mobilization stage
  – Become aware of the stressor
  – "Fight or flight"

• Resistance stage
  – Preparation to fight the stressor
  – Stress continues
  – Physiological arousal continues at higher point

• Exhaustion stage
  – Resources run out, arousal decreases
  – Negative consequences of stress appear

The Interactional Model (Folkman and Lazarus, 1984)

Stressor
An event occurs.

Primary appraisal
How do I feel about this?

Secondary appraisal
How can I cope with this?

Outcome
Stress if I cannot cope.
5 Myths About Stress

- Stress is the same for everyone
- Stress is always bad for you
- Stress is everywhere so you can’t do anything about it
- No symptoms = no stress
- Only major symptoms of stress deserve attention

(American Psychological Association)

Implications of Stress

- Parents less “available” on the unit
  - Physically
  - Psychologically
  - Distant, distracted, less focused
  - Impact on infant attachment, staff teaching
- Parents with high level of distress
  - Communication issues/Lack of understanding
  - Immobilization/Denial
  - Irritability

Responses

- Not all reactions are problematic
  - Adaptive
    - Self-care, use of resources
  - Functional
    - Hyperarousal = more alert, active, focused
    - Positive coping
      - Revising priorities, closer relationships
  - Problematic
    - Prolonged
    - Distressing
    - Interferes with daily functioning

System of factors:
Be aware of what is at play

[Diagram of the system of factors involving medical staff, child, family, and other stressors]

Pre-existing risk factors

- Mental health issues
- Cognitive/learning difficulties
- Substance use/abuse
- Low resources (Freuli, 2000)
- Personality characteristics
- Previous trauma
- Previous loss
- Infertility

Model of Pediatric Medical Traumatic Stress

[Diagram of the model of pediatric medical traumatic stress]

Family factors to consider

- Family functioning
  - Healthy vs. unhealthy interactions
  - Cohesion vs. conflict
  - Communication, problem solving, affect management, interpersonal

- Family demands/support
  - Number of other children
  - Location of family & social support
  - Other demands (e.g., ill parents)
  - Extended family support
    - Is it available?
    - Is it supportive?

Potentially Traumatic Events (PTE)

- Prenatal Diagnosis
- Pregnancy/Delivery
- NICU admission
- Discharge to home

Experience of the PTE

- Parents perception is key → coping
  - How parents perceive diagnosis, NICU & associated events influences how they respond
  - Perception is not always others’ reality
    - Can lead to conflicts

What can we do to reduce the trauma?

Phase I: Peri-trauma

- GOAL: To change subjective experience of the potentially traumatic event (PTE)
- SOLUTIONS:
  - Communication
  - Empathy
  - Education
  - Staff support
Phase II: Early, Ongoing Evolving

- Early Acute responses
  - Disengagement
  - Avoidance
  - Anxiety/Panic
  - Depression
  - Intrusive thoughts
- Ongoing, evolving responses with time

Resilience

- Many NICU families cope extremely well
  - Find meaning
  - Stay grounded
  - Think positively
  - Adapt to changing circumstances
  - Utilize their resources & supports
  - Present & future oriented

Traumatic Stress

- Reaction to a traumatic event
- Psychological and physiological symptoms
  - Re-experiencing
    - Intrusive, unwanted thoughts about experience
    - Feeling distressed
  - Avoidance
    - Avoiding reminders or thinking/talking about event
    - Emotionally numb, detached
  - Hyper-arousal
    - Hypervigilance, exaggerated startle response
    - Increased irritability, difficulty sleeping, poor concentration

What does this have to do with NICU?

- PTSD in regards to returning soldiers
  - Diagnosis originated from experiences of war vets
- PTSD can occur from range of events
  - Murder, rape, crime, health condition, terrorism
  - Criteria changed in 1994 more inclusive
- Clinicians and researchers studying hospital settings
  - Traumatic childbirth
  - NICU and PICU
Trauma in Different Battlefields

<table>
<thead>
<tr>
<th>Life-threatening situation</th>
<th>COMBAT</th>
<th>NICU</th>
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<tbody>
<tr>
<td>High pressure</td>
<td>✔️</td>
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<tr>
<td>High stress</td>
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<tr>
<td>Unfamiliar environment</td>
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<tr>
<td>Unexpected Events</td>
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<td>Witness to Death</td>
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Common responses to traumatic event

- **EMOTIONAL**
  - Shock
  - Rage
  - Anger
  - Guilt
  - Vulnerability
  - Helplessness

- **COGNITIVE**
  - Disbelief
  - Confusion
  - Self-blame
  - Disorientation
  - Poor concentration

- **BEHAVIORAL**
  - Fatigue
  - Insomnia
  - Nightmares
  - Hyperarousal
  - Startle response
  - Avoidance

- **PSYCHOSOCIAL**
  - Alienation
  - Social withdrawal
  - Relationship issues
  - Substance abuse
  - Vocational impairment

What we may see in NICU families

<table>
<thead>
<tr>
<th>SITUATION</th>
<th>THOUGHTS/FEELINGS</th>
<th>BEHAVIORS</th>
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<tbody>
<tr>
<td>Child’s medical status</td>
<td>Anxiety, Hopelessness, Uncertainty, Anger</td>
<td>Efforts to take control, Hypervigilance, Defensiveness, Irritability, Avoidance</td>
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<td>Change in providers/unit</td>
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<td>Unfamiliar environment</td>
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<td>Novel situation</td>
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<td>Outside stressors</td>
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DSM-IV Criteria for PTSD

**A. STRESSOR**

Exposure to an extreme traumatic stressor that involves actual or threatened death or serious injury, or other threat to one’s physical integrity;

- experiencing an event
- witnessing an event
- Indirect- learning about event

**B. INTRUSIVE RECOLLECTION** (1 out of 5)

1) recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions.
2) recurrent distressing dreams of the event
3) acting or feeling as if the traumatic event were recurring
4) intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.
5) physiological reactivity at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.

**C. AVOIDANT/NUMBING** (1 out of 2)

1) Efforts to avoid thoughts, feelings, or conversations associated with the trauma
2) Efforts to avoid activities, places, or people that arouse recollections of the trauma
DSM-IV Criteria for PTSD

D. INCREASED AROUSAL (2 out of 7)
1) difficulty falling or staying asleep
2) irritability or outbursts of anger
3) difficulty concentrating
4) hypervigilance
5) exaggerated startle response

E. DURATION
Greater than one month.

F. FUNCTIONAL SIGNIFICANCE
Clinically significant distress or impairment in social, occupational, or other important areas of functioning.

• Specify if:
  - Acute: if duration of symptoms is less than 3 months
  - Chronic: if duration of symptoms is 3 months or more
• Specify if:
  - With Delayed Onset: if onset of symptoms is at least 6 months after the stressor

DSM-IV Criteria for ASD

• Acute Stress Disorder
  - Milder form
  - Symptoms must occur
    • Last at least 3 days
    • Within 1 month of traumatic event
    • Resolve within first month
    • If symptoms persist beyond one month and meet criteria for PTSD, then diagnosis is changed
  - Studies estimate approximately 75% of individuals with ASD develop PTSD (Buehrer & Harvey, 2000)

Prevalence of PTSD

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<tr>
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<th>Mothers</th>
<th>Fathers</th>
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<tr>
<td>General Population</td>
<td>10.4%</td>
<td>5%</td>
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<td>All Childbirths</td>
<td>2-14%</td>
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<tr>
<td>NICU Admission</td>
<td>26-41%</td>
<td>8-33%</td>
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(Kessler et al., 1995; Pfefferbaum et al., 2003)

Phase III- Longer Term

• GOAL: To decrease severity of PTSS
• SOLUTIONS:
  – Ongoing follow-up care
  – Pre-discharge planning
  – Knowledge/Education
  – Community support
Assessment of ASD/PTSD

- Screening for risk
  - Clinical Interview
  - Questionnaires –IES-R, PTSD checklist
- Referral for diagnosis
- Behavioral Assessment Tests
  - Not used regularly
- Psychophysiological Assessment
  - Not practical

Pediatric Psychosocial Preventative Health Model

“The goal of the PPPHM is to conceptualize how families of acutely and chronically ill children might be provided psychosocial support to match their level of need and risk.”

(Kazak, 2006)

Secondary Traumatic Stress

- Impact of witnessing others’ traumas
  - Pediatrics in particular due to value of caring for children (Vredenburgh, 1992; Robins et al., 2009)
  - Cumulative effect (Weiss et al., 1995)
  - “Culture of silence” and “can do” culture
  - Years in direct care and greater blurring of caregiver boundaries predictive of greater burnout and compassion fatigue (Robins et al., 2009)
  - 82% pediatricians/NICU nurses 1 symptom of PTSD and 21% positive screen (Czaja et al. 2012)
Staff Support
• Important to monitor our own responses and coping
• Seek support when needed
• Practice good professionals boundaries
• Communicate with each other
• Practice good self-care
  – Stress management
  – Work-life balance
  – Planned time off

Interdisciplinary Recommendations for Psychosocial Support of NICU Parents

Goal of the NPA Workgroup
"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."
– Hynan & Hall, J Perinatol, 2016

Articles on Comprehensive Family Support

Members from these Organizations

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<tr>
<td>Academy of Neonatal Nursing</td>
<td>National Perinatal Association</td>
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<tr>
<td>Perinatal Section of American Academy of Pediatrics</td>
<td>National Prematurity Infant Health Coalition</td>
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<tr>
<td>Association of Women’s Health, Obstetric and Neonatal Nurses</td>
<td>Nurse Family Partnership</td>
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<td>Council of International Neonatal Nurses</td>
<td>Oklahoma Infant Alliance</td>
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<td>Healthy Mothers, Healthy Babies</td>
<td>Postpartum Support International</td>
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<td>National Association of Neonatal Nurses</td>
<td>Prematurity Foundation</td>
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<td>National Association of Neonatal Therapists</td>
<td>Society of Maternal Fetal Medicine</td>
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<td>National Association of Pediatric Nurse Practitioners</td>
<td>Society of Pediatric Psychology</td>
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<td>National Association of Perinatal Social Workers</td>
<td>Special Care/Special Kids</td>
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<td>Transcultural Nursing Association</td>
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**Participating Parent Support Organizations**

- Eden’s Garden
- Graham’s Foundation
- Hand to Hold
- NICU Helping Hands
- Neonatal Intensive Care Unit Parent Support at St. John’s Mercy Hospital in St. Louis
- Parent to Parent Support of Salt Lake City
- Postpartum Support International
- Preeclampsia Foundation
- Preemie Parent Alliance
- Zoe Rose Memorial Foundation

**Components of Comprehensive Family Support in the NICU**

- Mental Health Professionals
- Peer-to-peer & Family Support
- Palliative & Bereavement Care
- Post-Discharge Follow-up
- Staff Education & Support
- Family-centered Developmental Care

**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 doctoral level psychologist on staff, with roles overlapping re counseling, screening, educating staff and teaching parenting skills.
2. NMHPs should meet with parents within 1-3 days and screen for emotional distress within the first wk after admission; repeat 48 hrs. prior to discharge.
3. Layered levels of emotional support should be available to all parents.

**Role of NICU Psychologist**

- Focus on medical diagnoses/demands & caregivers’ thoughts/feelings/behaviors
- Advocate for family-centered care
- Liaison between medical team and family
- Collaborate with psychiatrist or other mental health providers who may be already involved

**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

**With families, can address:**
- Anxiety/Depression/Trauma
- Stress management
- Poor self-care
- Maladaptive reactions to situation
- Family problem solving & communication
- Sibling adjustment
- Grief/loss

**With staff, can address:**
- Relationship building
- Communication
Toolkit of Resources

- www.support4NICUparents.org (a program of the National Perinatal Association)
- There are resources for professionals and for parents.

Summary

- NICU experience can cause significant and long-lasting distress for some families
- Important to identify those who are at-risk and experiencing difficulties
  - Exact diagnostic labels less important
- Staff can also be susceptible
- Despite stressors, families can be resilient
- NICU experience can also bring about positive changes for some families

THANK YOU!

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