When Does

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For parents, NICU + BABY = ?

= Joyous?
= Exciting?
= Hopeful?
= Upsetting?
= Frightening?
= Worrisome?
= Stressful?
= Traumatic???

Any or all of the above!
Overview

- How do we define traumatic stress?
- What can make the NICU experience traumatic?
- What are the predictors of post-traumatic stress?
- How can we tell when a family is at-risk?
- What can we do to help?
Objectives

- Examine nature of parental distress in the NICU
- Define post-traumatic stress in the context of the NICU
- Review recent research
- Discuss implications for interventions in the NICU and after discharge
**Definitions: Traumatic Stress**

- Reaction to a traumatic event
- Psychological and physiological symptoms
  - **Re-experiencing**
    - Intrusive, unwanted thoughts about experience
    - Feeling distressed
    - Nightmares, flashbacks
  - **Avoidance**
    - Avoiding reminders or thinking/talking about event
    - Emotionally numb, detached
  - **Hyper-arousal**
    - Hypervigilance, exaggerated startle response
    - Increased irritability
    - Difficulty sleeping, concentrating
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
- Parents with PTSD? But they didn’t go to war....
  - Event witness
- Clinicians and researchers studying hospital settings
  - Traumatic childbirth
  - NICU and PICU
### Trauma in Different Battlefields

<table>
<thead>
<tr>
<th></th>
<th>COMBAT</th>
<th>NICU</th>
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<tr>
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<td>High stress</td>
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<td>Unfamiliar environment</td>
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<td>Unexpected Events</td>
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<td>Witness to Death</td>
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# Common responses to traumatic event

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<tr>
<th>EMOTIONAL</th>
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<tr>
<td>SHOCK</td>
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<td>SOCIAL WITHDRAWAL</td>
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<td>NIGHTMARES</td>
<td>RELATIONSHIP ISSUES</td>
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<td>HYPERAROUSAL</td>
<td>SUBSTANCE ABUSE</td>
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<td>STARTLE RESPONSE</td>
<td>VOCATIONAL IMPAIRMENT</td>
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<td>AVOIDANCE</td>
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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
A. STRESSOR

1. 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
   - learning about an event

2. Response must include:
   - Intense fear
   - Horror
   - Hopelessness
B. INTRUSIVE RECOLLECTION

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) 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
3) Inability to recall an important aspect of the trauma
4) Markedly diminished interest or participation in significant activities
5) Feeling of detachment or estrangement from others
6) Restricted range of affect (e.g., unable to have loving feelings)
7) Sense of a foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life span)
DSM-IV Criteria for PTSD

D. INCREASED AROUSAL

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
Acute Stress Disorder

- Milder form
- Symptoms must occur
  - Within 4 weeks of traumatic event
  - Resolve within that 4 week period
  - 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 (Buehler & Harvey, 2000)
Assessment of ASD/PTSD

- Clinical Interview
- Structured Interview
- Questionnaires
  - Acute Stress Disorder Scale
  - Stanford Acute Stress Reaction Questionnaire
  - Post-Traumatic Diagnostic Scale
  - Distress Events Questionnaire
- Behavioral Assessment Tests
  - Not used regularly
- Psychophysiological Assessment
  - Not practical
Treatment of ASD/PTSD

- Counseling
  - Debriefing
  - Cognitive-Behavioral Therapy
    - Cognitive restructuring/reframing
  - Coping strategies
  - Supportive therapy
- Medication (when warranted)
- EMDR
  - Empirical support mixed
Implications of PTSD/ASD

Parents less “available” on the unit
- Physically
  - Avoidant
- Psychologically
  - Distant, distracted, less focused, disociated
- Impact on infant attachment, staff teaching

Parents with high level of distress
- Communication issues
- Lack of understanding
- Immobilization
- Denial
- Irritability
So is this the “right” model to look at parents in the NICU?

- Is it PTSD per se? Overlap with depression/anxiety?
- Is the NICU experience akin to combat?

Yes
- NICU hospitalization meets criteria for stressor
- Reactions can be severe and longlasting

No
- Usually subclinical
- Usually resolve
II. Model of Pediatric Medical Traumatic Stress
Model of Pediatric Medical Traumatic Stress

Phase I: Peri-Trauma

- Pre-existing risk factors
  - Previous trauma
  - Previous mental health issues
  - Social support
  - Life stressors: parental health, finances, work, relationship, other children at home

- Characteristics of the event
  - Emergency, unexpected delivery
  - Near death experience for mother
  - Newborn health issues
Phase I: Peri-trauma

- Potentially Traumatic Events (NICU)
  - Sounds, sights of NICU
  - Surgery
  - Complications
  - Changes in prognosis, outcomes

- Parents perceptions is key → coping
  - How parents perceive the NICU and associated events influences how they respond
  - Perception is not always others’ reality
    - Can lead to conflicts
Model of Pediatric Medical Traumatic Stress

Phase I: Peri-trauma

GOAL: To change subjective experience of the potentially traumatic event (PTE)

SOLUTIONS:
- Communication
- Empathy
- Staff support
- Educating families
Model of Pediatric Medical Traumatic Stress

Phase II: Early, Ongoing Evolving

- Early Acute responses
  - Disengagement
  - Avoidance
  - Anxiety/Panic
  - Depression
  - Intrusive thoughts

- Ongoing, evolving responses with time
Phase II: Early, Ongoing Evolving

GOAL: to prevent PTSS

SOLUTIONS:
- Family Centered Care
- Parent involvement/empowerment
- Early assessment/intervention
- Improve coping skills
- Encourage self-care
- Support services
- Preparation and education
Model of Pediatric Medical Traumatic Stress

Phase III- Longer Term

Long-Term Responses PTSS
- Symptoms maintain over extended period of time
- Post-discharge
- Impairment of functioning, parenting

GOAL: To decrease severity of PTSS

SOLUTIONS:
- Ongoing follow-up care
- Pre-discharge planning
- Knowledge/Education
- Community support
III. Research
Parental traumatic stress: PTSD

Poverty exacerbates vulnerability for PTSD symptoms (Breslau et al., 1991)
- Also more likely to deliver pre-term at-risk infant requiring NICU admission (Parker et al., 1994)

Mothers with histories of traumatic events, more likely to delivery prematurely (Misra et al., 2001)

PTSD symptoms correlate with poorer physical health in adults and children
- Parental PTSD symptoms predicted children’s later sleep and eating problems as well as less sensitive and controlling maternal behaviors (Pierrehumbert et al., 2003; Muller-Nix et al., 2004)
Prevalence rates of PTSD

- PTSD lifetime prevalence rate is 6.8% (Kessler et al., 2005)
  - 9.7% for women, 3.6% for men
- Following childbirth:
  - 1.5-6% mothers reported PTSS (Bellini, 2009)
- Following premature birth:
  - 26-41% mothers reported PTSS (Pierrehumbert et al., 2003)
- Symptoms most often endorsed
  - Hyperarousal, hypervigilance
  - Avoidance
  - Re-experiencing
- Lower than rates of PPD
Pediatric Chronic Illness

Cancer

- Elevated levels of PTSS for mothers and fathers
  - Nearly 20% of families had parent who met criteria for PTSD (Kazak et al., 2004)

PICU admission

- 27% of parents reported PTSD vs. 7% from hospital (Rees et al., 2004)
- 32% met criteria for ASD, 21% met PTSD (Balluffi et al., 2004)

Severe injury

- 1 week post: 28% parents report high levels of PTSS (Zatrick et al., 2006)
44% of NICU mothers met criteria for ASD 2-4 weeks postpartum (Shaw at al., 2006)
23% of NICU mother vs. 3% WBN mothers met criteria for ASD 1 week postpartum
At discharge, greater percentage of mothers of infants at high risk reported intrusive memories and avoidance of events related to childbirth as compared to parents of full term and premature healthy babies (DeMier at al., 1996)
At 6 months corrected age, over half of mothers interviewed had at least 3 symptoms of PTS and # of symptoms was related to maternal well-being (Holditch-Davis et al., 2003)
NICU: Longitudinal Studies

Studies suggest decrease in PTSS over the first year

- Not consistent (Miles et al., 2007)
- At 24 months, 65% of mothers who were reported high level of PTSS initially remained high on PTSS (Holditch-Davis et al., 2009)

Distressing memories of the NICU continue for 6 months or more (Reichman et al., 2000)

Mothers of VLBW infants (high and low risk) had more distress than mothers of term infants at 1 month. (Singer et al., 2003)

- 2 years: High risk VLBW children > low risk VBLW and term children
- 3 years: For high risk VLBW, parenting stress remained greater
Sex differences

Mothers more poorly adjusted and more anxious, hostile and depressed than fathers (Doering et al., 1999)

- Both mothers’ and fathers’ emotional distress above normative levels

Fathers have delayed reaction that may result in greater emotional distress later on post-discharge
Small samples
Mothers overrepresented
Most assessments prior to discharge
  - Easy to confuse PTSS, ASD, PTSD
  - Can’t diagnose PTSD until at least one month of symptoms
Few longitudinal
Very few interventions
Lack of appropriate comparison samples
IV.
Implications for Intervention
Pediatric Preventative Psychosocial Health Model

Clinical
- 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

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Developed by Medical Traumatic Stress Working Group of the National Child Traumatic Stress Network (NCTSN)

- Reduce DISTRESS
- Promote EMOTIONAL SUPPORT
- Remember the FAMILY
Reduce Distress

- Actively assess and treat infants’ pain
- Provide parents with information and choices about decision-making
- Ask about parents’ fears and worries
- Provide reassurance and realistic hope
Encourage parents to be with their baby as much as they prefer

Empower parents to comfort and help their baby
- Teach ways to help stimulate and care for their child
- Teach ways to help soothe the infant
- Examples: Kangaroo Care, massage, play, sing, feed, cues, etc.
Assess family distress and other life stressors
  - Not just parents, but grandparents, siblings
Identify family strengths and coping resources
Encourage parents to use available coping resources and support
  - Family/friends
  - Community/church
Remember the Family

Meet the family where they are
  Match coping styles

Involve psychosocial staff in team-based approach for those at higher risk
  SW, Chaplain, Psychologist
  Provide support services during and after discharge
V. Staff Issues
Secondary Traumatic Stress

- It ain’t just the parents, folks...
- Healthcare providers
- 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)
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 tome off
VI.
Summary and Future Directions
Summary

- NICU experience can cause significant and long-lasting distress for some families
  - ASD and PTSD can result
- 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
Clinical Service

- Family Centered Care
  - Involve parents as much as they are able and willing
  - Partner with families
  - COPE program

- Support services
  - Social workers
  - Chaplains
  - Psychologists
  - Parent Liaisons
  - Community resources
Research

- Study the relationship and uniqueness of depression and PTSS
- PTSS and provider-parent communications
- Study effectiveness of interventions through randomized controlled trials
- Predictors of traumatic response
  - Role of social support and past traumas
  - Impact of readmissions to NICU
- Long-term prospective studies that include home transition period and beyond
  - Parenting effects
- Post-traumatic growth
Questions?
Resources

- National Center for PTSD (NCPTSD)
  - [http://www.ptsd.va.gov/](http://www.ptsd.va.gov/)

- National Child Traumatic Stress Network (NCTSN)
  - [http://www.nctsn.net/](http://www.nctsn.net/)

- March of Dimes - Parenting in the NICU


