Medical PTSD in the NICU: Helping Families Cope

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- NICU Social Workers
- Developmental Team
- GCRC Nurses and Research Staff
- Research Assistants
- NICU Parents

Outline

- Definitions: Posttraumatic Stress Disorder (PTSD), Medical PTSD, and Acute Stress Disorder (ASD)

- Review of ASD and PTSD in the NICU

- Discussion of intervention studies conducted with NICU parents

- Practical strategies to help parents cope
Posttraumatic Stress Disorder (PTSD)

- Exposure to traumatic event in which a person experiences, witnesses, or is confronted with events that involve actual or threatened death or serious injury, or threat to physical integrity
- Response involves fear, helplessness, or horror
- Three symptom clusters:
  - Re-experiencing the traumatic event
    - Recurrent recollections of the event (i.e., images, thoughts or perceptions)
    - Recurrent dreams
    - Feeling as if the event was recurring
    - Reactivity to cues that resemble an aspect of the event
  - Avoiding reminders of the event
    - Avoiding thoughts, feelings, conversations, activities, places or people that are associated with the event
  - Increased arousal
    - Sleep disturbances
    - Irritability
    - Exaggerated startle response

PTSD: Additional Criteria

- Symptoms must be present for at least one month
- Must cause significant distress or impairment in functioning

Now…
  - What is unique about Medical PTSD?

Medical PTSD

<table>
<thead>
<tr>
<th>PTSD Symptoms</th>
<th>Non-medical Posttraumatic Stress Disorder</th>
<th>Medical Posttraumatic Stress Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exposure to traumatic event</td>
<td>Recurrence of traumatic event that involves actual or threatened death or serious injury, or a threat to the physical integrity of self or others</td>
<td>Exposure to event that involves a serious life event. Information stressor.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Traumatic event is located internally and cannot be separated from the individual.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ongoing stress may be due to stress of future illness resistance.</td>
</tr>
</tbody>
</table>

Source: Green et al., 1997
### Medical PTSD

#### PTSD Symptoms

<table>
<thead>
<tr>
<th></th>
<th>Non-medical Posttraumatic Stress Disorder</th>
<th>Medical Posttraumatic Stress Disorder</th>
</tr>
</thead>
</table>
| Re-experiencing      | Recurrent and intrusive distressing recollections, dreams or flashbacks of the traumatic event. | Recurrent and intrusive recollections about the diagnosis or treatment of the illness.  
Recurrent, future-oriented fears about the treatment or prognosis of the illness, reoccurrence of the illness, or death. |
| Avoidance            | Efforts to avoid activities or situations that remind one of the traumatic event.  
Nonadherence with medical treatment.  
Avoidance of exposure to the trauma may be difficult since many of the cues are internally located or related to ongoing treatment. |
| Arousal              | Hypervigilance to external cues that remind one of the traumatic event.  
Hypervigilance to medical cues that remind one of traumatic aspects of the treatment.  
Hypervigilance to somatic symptoms that may indicate reoccurrence of illness.  
Hyperactivity.  
Increased frequency of arousal symptoms of PTSD with medical symptoms. | |

Source: Green et al., 1997
Acute Stress Disorder

Similar to symptoms of PTSD

Two biggest differences are:

- Symptoms last between 2 days and 4 weeks
- Presence of dissociative symptoms (e.g.,
  derealization, “being in a daze”, sense of numbing
  or detachment)

PTSD in Medical Illness

Recent meta-analysis of prevalence of PTSD
in parents of children with a chronic illness:

- 22.8% of parents
- Higher prevalence in mothers (19.6%) than fathers (11.6%)

(Cabizuca et al., 2009)

This study did not look at NICU parents, but
others have…

Study 1: Design

Parents of infants hospitalized in the NICU were recruited
at LPCH where they were asked to participate in a study
of their reaction to their infant’s NICU hospitalization

This study utilized a longitudinal design; parents
completed self-report questionnaires at two time points:

- Baseline: 2-4 weeks following the hospitalization of their
  infant
- Follow-up: 4 months after the birth of their infant

(Shaw et al., 2006)
Demographic Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mothers</th>
<th>Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnic origin</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>15</td>
<td>12</td>
</tr>
<tr>
<td>Asian</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>African-American</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>n</td>
<td>60.0</td>
<td>92.3</td>
</tr>
<tr>
<td>%</td>
<td>20.0</td>
<td>7.7</td>
</tr>
<tr>
<td>Academic degree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>B.A./B.S.</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>M.A.</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>PhD/M.D./J.D.</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>n</td>
<td>5.6</td>
<td>41.7</td>
</tr>
<tr>
<td>%</td>
<td>72.2</td>
<td>50.0</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Part-time</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>Full-time</td>
<td>14</td>
<td>100.0</td>
</tr>
<tr>
<td>n</td>
<td>28.0</td>
<td>0.0</td>
</tr>
<tr>
<td>%</td>
<td>56.0</td>
<td>100.0</td>
</tr>
<tr>
<td>Annual family income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$20,000 - $39,999</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>$40,000 - $59,999</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>$60,000 - $79,999</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>$80,000 - $99,999</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>$100,000+</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>n</td>
<td>31.6</td>
<td>33.3</td>
</tr>
<tr>
<td>%</td>
<td>55.6</td>
<td>66.6</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Married</td>
<td>20</td>
<td>15</td>
</tr>
<tr>
<td>n</td>
<td>13.0</td>
<td>100.0</td>
</tr>
<tr>
<td>%</td>
<td>87.0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

Mean  SD
Age (years) 33.96  6.49

Infant Variables

| Variable                      | n | %  
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Family intervention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IVF (in-vitro procedure)</td>
<td>7</td>
<td>25.0</td>
</tr>
<tr>
<td>Other intervention</td>
<td>2</td>
<td>7.4</td>
</tr>
<tr>
<td>Gestational age (weeks)</td>
<td>31.66</td>
<td>4.91</td>
</tr>
<tr>
<td>Birth weight (grams)</td>
<td>1811.44</td>
<td>996.97</td>
</tr>
<tr>
<td>Apgar score, 1 min.</td>
<td>5.96</td>
<td>2.33</td>
</tr>
<tr>
<td>Apgar score, 10 min.</td>
<td>7.83</td>
<td>1.40</td>
</tr>
<tr>
<td>Days in NICU</td>
<td>37.40</td>
<td>35.47</td>
</tr>
</tbody>
</table>

Study 1: Measures

- **Demographic Questionnaire**: Gestational age, birth weight, Apgar scores, length of stay.
- **Parental Stressor Scale, Neonatal Intensive Care Unit (PSS, NICU)**: To assess parent perceptions of NICU-related stressors.
- **Stanford Acute Stress Reaction Questionnaire (SASRQ)**: To assess ASD symptoms.
- **Davidson Trauma Scale (DTS)**: To assess symptoms of PTSD.
- **Beck Depression Inventory, Second Edition (BDI-II)**: To assess symptoms of depression.
### Parental Stressor Scale: NICU (PSS:NICU)

<table>
<thead>
<tr>
<th>Category</th>
<th>Items</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sights and Sounds of the NICU</td>
<td>5</td>
<td>The appearance and sounds of the physical environment of the NICU.</td>
</tr>
<tr>
<td>Parental Role Alteration</td>
<td>11</td>
<td>Changes in the expected parental role.</td>
</tr>
<tr>
<td>Staff Relationships</td>
<td>11</td>
<td>Staff behaviors and communication.</td>
</tr>
<tr>
<td>Infant Behavior and Appearance</td>
<td>15</td>
<td>Appearance and behaviors of the sick infant.</td>
</tr>
</tbody>
</table>

### Results: Study 1

- 44% of mothers met criteria for ASD
- Fathers reported symptoms of ASD but none met full criteria
- Mothers reported higher levels of depressive symptoms than fathers

### Results: Study 1 (Cont’d)

- ASD symptoms were influenced by stressors specific to the NICU environment and were most strongly correlated with concerns regarding parental role alteration (especially for mothers)
- Severity of depression was primarily related to the infant’s behavior and appearance
Just to Compare…

- 59 NICU mothers vs. 60 well baby nursery (WBN) mothers
  - 23% of NICU mothers met criteria for ASD
  - 3% of WBN mothers met criteria for ASD

(Vanderbilt et al., 2009)

Follow-Up Study

- 18 parents completed follow-up measures 4-months after the birth

Interesting gender differences (but keep in mind the small sample size!)

(Shaw et al., 2009)

### PTSD Diagnosis by Parent Gender

<table>
<thead>
<tr>
<th>PTSD Status</th>
<th>Mothers (N=11)</th>
<th>Fathers (N=6)</th>
<th>Total (N=17)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>At Risk for PTSD</td>
<td>6</td>
<td>55</td>
<td>4</td>
</tr>
<tr>
<td>Likely Diagnosis</td>
<td>1</td>
<td>9</td>
<td>2</td>
</tr>
</tbody>
</table>
Results: Follow-Up Study

- Strong correlation between developing ASD initially and the future onset of PTSD symptoms
- Increase in fathers’ symptoms at follow-up:
  - ASD at baseline = 0%; PTSD at follow up = 33%
- Symptoms of PTSD correlated with baseline symptoms of depression and to stress induced by the sights and sounds of the NICU

High Rates of ASD & PTSD

- Recent larger study
  - Sample: 86 mothers, 41 fathers
  - Time points: Admission & 1-month follow-up
  - Baseline:
    - 35% of mothers and 24% of fathers met criteria for ASD
  - Follow-up:
    - 15% of mothers and 8% of fathers met criteria for PTSD
    - Rates of postpartum depression (PPD) were high
    - 16% met criteria for PPD and PTSD

Taking a Closer Look

- Although prevalence varies across studies, research has demonstrated that parents of premature infants have higher indices of PTSD than control parents
- Parents report moderate to high levels of stress but not continuous stress
- Peak of anxiety occurs soon after admission

(Leffowitz et al., 2010)
Parents’ Experience in the NICU

In addition to anxiety, ASD, PTSD, and depression, researchers have found guilt, helplessness, sadness over the loss of the “perfect” child, and parental stress.

Alteration in parental role is consistently rated as the most distressing source of stress:
- Separation from the infant
- Feelings of helplessness in the parental role
- Limitations on the ability to provide care

Gender Differences

**Mothers:**
- Greater levels of parental distress
- More negative assessment of severity of infant’s problems
- Possible role of postpartum hormonal changes
- Tendency to use escapist coping mechanisms and mobilization of social support

**Fathers:**
- Less emotionally affected
- Tendency to minimize outward emotional response
- Tendency to minimize severity of the problem and to take instrumental action against source of stress
- Spend more energy trying to assist spouse during the crisis
- Tend to report less need for support in the NICU

Impact on Family

Anxiety, depression, and PTSD can negatively impact parental behavior.

**Examples of short term issues:**
- Parental distress can affect infant sleep and eating patterns (Pierrehumbert et al., 2003)
- Difficult parent-infant interactions

**Examples of long term issues:**
- Overprotective and fail to set appropriate limits
- Difficult parent-child interactions
- Perceive their child to be physically vulnerable → greater rates of health care utilization
- Impact on cognitive development and behavior problems
Interventions

Interventions have focused on either:

- Improving parent-infant interactions with the goal of reducing parental stress/psychological symptoms
- Directly targeting symptoms of psychological distress

Paucity of interventions that focus on PTSD symptoms

Improving Parent-Infant Interactions

These interventions often include:

- Information about infant characteristics such as appearance, behavior, and temperament
- Enhancement of parent-infant interactions

Examples:

- Educational-behavioral intervention; Creating Opportunities for Parent Empowerment (COPE) (Melnyk et al., 2006)
- Family-based intervention (also included identifying support and discharge planning) (Meyer et al., 1994)
- Early intervention program (8 sessions prior to discharge, 4 home visits) (Karenska et al., 2000, 2009)
- Kangaroo care (Anderson et al., 2003)

Decreasing Psychological Symptoms

Journaling about the experience

- Results: Reduced psychological distress (Barr & Singer, 2001)

Support from a parent “buddy”

- Results: Effective with helping mothers cope with stress (Preyde & Ardal, 2003)

Early crisis intervention plus support at critical times in infant’s care

- Results: Mothers in the treatment group reported lower levels of trauma symptoms (Jutaz & Potts, 2005)
Decreasing Psychological Symptoms

- **Cognitive-behavioral skills:**
  - Treatment Group 1: Brief videotape about active problem-focused coping strategies (e.g., modeling assertive communication)
  - Treatment Group 2: Brief videotape about emotion-focused coping strategies (e.g., mental imagery, positive self-talk)
  - Control Group: Brief promotional video about the hospital
  - Results: Maternal anxiety lower in both treatment groups (Cobella et al., 1990)

- **Group CBT intervention**
  - Results: Intervention did not prevent postnatal depression (Bagan et al, 2004)

Study 2: Intervention

- Pilot study of a brief CBT intervention
- Selected a CBT intervention due to known effectiveness in treating trauma and depressive symptoms
- Modeled after treatments that have proven effective in reducing anxiety in parents of children with other types of medical conditions (e.g., Jay & Elliot, 1990)
- Important considerations: To be time & cost effective and practical for a busy NICU! (Bernard et al., in press)

Study 2: Design

- Random assignment to either the standard care group or the treatment group
- Standard Care Group: Typical care provided to parents who have an infant in the NICU
- Treatment Group: Received three 45-55 minute sessions designed to teach parents cognitive-behaviorally based skills to manage their symptoms of anxiety
Session 1

- Information about the NICU
- Normalization of the NICU and infant’s appearance
- Common thoughts/concerns of parents
- How to improve communication with NICU staff

Common Parental Concerns

- Guilt
  - “This is my fault.”
  - “What could I have done to prevent this?”
- Anger
  - “This isn’t fair. It shouldn’t be this way.”
- Sadness
  - Upset over the loss of a “normal” pregnancy and birth

Common Parental Concerns

- Worried
  - “My baby looks like he/she is in pain.”
  - “Is he/she going to be okay?”
  - “What is the future health of my baby?”
- Scared
  - “He/she looks so fragile; I’m scared I might hurt him/her.”
- Confused
  - “Why did this happen?”
  - “The nurse is taking care of my baby, but where do I fit in?”
Session 2

- Cognitive restructuring techniques
  - “Examining the evidence”
  - “What would I tell a friend”

- Positive self-statements
  - “This is hard right now but I can handle it”

Session 3

- Relaxation skills
  - Deep breathing
  - Progressive muscle relaxation (PMR)

Study 2: Hypotheses

- Parents will report high levels of initial depressive and trauma-related symptoms

- Parents who receive the intervention will report lower symptom levels at follow-up
Study 2: Measures

- Baseline:
  - Stanford Acute Stress Reaction Questionnaire (SASRQ)
  - Davidson Trauma Scale (DTS)
  - Beck Depression Inventory-Second Edition (BDI-II)
  - Parental Stressor Scale: NICU

- Follow-up: One month post-discharge from the hospital
  - Davidson Trauma Scale (DTS)
  - BDI-II

Baseline Maternal & Infant Characteristics by Treatment Group

<table>
<thead>
<tr>
<th>Maternal &amp; Infant Characteristics at Baseline</th>
<th>Control (n=25)</th>
<th>Intervention (n=25)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal Demographics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (M, SD)</td>
<td>32.0, 5.6</td>
<td>33.3, 4.2</td>
<td>.35</td>
</tr>
<tr>
<td>Race/Ethnicity (%):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian (n=28)</td>
<td>61%</td>
<td>39%</td>
<td>.14</td>
</tr>
<tr>
<td>Hispanic (n=10)</td>
<td>20%</td>
<td>80%</td>
<td></td>
</tr>
<tr>
<td>Asian (n=10)</td>
<td>50%</td>
<td>50%</td>
<td></td>
</tr>
<tr>
<td>Other (n=2)</td>
<td>50%</td>
<td>50%</td>
<td></td>
</tr>
<tr>
<td>Marital Status (%):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single/Separated/Divorced (n=3)</td>
<td>33%</td>
<td>67%</td>
<td>.99</td>
</tr>
<tr>
<td>Married/Partnered (n=47)</td>
<td>51%</td>
<td>49%</td>
<td></td>
</tr>
<tr>
<td>Education (yrs; M, SD):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.1, 2.9</td>
<td>15.6, 2.8</td>
<td>.53</td>
<td></td>
</tr>
<tr>
<td>Total Household Income Before Taxes (%):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; $20,000 - $59,999 (n=11)</td>
<td>45%</td>
<td>40%</td>
<td>.93</td>
</tr>
<tr>
<td>$60,000 - $99,999 (n=10)</td>
<td>40%</td>
<td>55%</td>
<td></td>
</tr>
<tr>
<td>≥ $100,000 (n=28)</td>
<td>54%</td>
<td>60%</td>
<td></td>
</tr>
</tbody>
</table>

Infant Characteristics

<table>
<thead>
<tr>
<th>Infant Characteristics</th>
<th>Control</th>
<th>Intervention</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gestational age (weeks; median, interquartile range)</td>
<td>33 (31, 34)</td>
<td>32 (29, 34)</td>
<td>.17</td>
</tr>
<tr>
<td>Birth weight (g; M, SD)</td>
<td>1855, 596</td>
<td>1659, 539</td>
<td>.23</td>
</tr>
<tr>
<td>Length of stay (days; median, interquartile range)</td>
<td>39 (27, 55)</td>
<td>40 (27, 60)</td>
<td>.77</td>
</tr>
</tbody>
</table>

Maternal Depression and Trauma Measures by Treatment Group

<table>
<thead>
<tr>
<th>Measure</th>
<th>Control (M, SE)</th>
<th>Intervention (M, SE)</th>
<th>Difference (M, SE)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BDI – II</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline (unadjusted)</td>
<td>14.9, 1.8</td>
<td>11.4, 1.7</td>
<td>3.5, 2.5</td>
<td>.17</td>
</tr>
<tr>
<td>Follow-up (adjusted for baseline BDI-II)</td>
<td>13.0, 1.8</td>
<td>8.2, 1.7</td>
<td>4.7, 2.5</td>
<td>.06</td>
</tr>
<tr>
<td>Trauma</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DTS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline (unadjusted)</td>
<td>30.9, 5.0</td>
<td>32.6, 5.0</td>
<td>7.7, 7.1</td>
<td>.34</td>
</tr>
<tr>
<td>Follow-up (adjusted for baseline DTS)</td>
<td>34.6, 4.7</td>
<td>26.5, 4.7</td>
<td>8.1, 6.7</td>
<td>.23</td>
</tr>
</tbody>
</table>
Discussion

- Mothers experienced high levels of symptoms initially and at follow-up
- Trend for mothers in the intervention group to report lower levels of depression
- Although scores on the measure of trauma symptoms were lower for the intervention group, results were not significant
- Vast majority of parents reported that the intervention was helpful

Future Directions

- Determine which subset of parents may need more intensive intervention
- Establish the optimal timing and duration of the intervention
- Conduct research with larger, more diverse samples
- Need for long-term follow-up studies

Future Directions (Cont’d)

- Recent consensus that interventions should address psychological symptoms AND parent-infant interaction patterns
- Stay tuned! Research is underway at Stanford…
How Can We Help?

- Provide education about common psychological reactions that may occur
- Ask about symptoms
  - Refer to a mental health professional if needed
- Help parents establish their role in the NICU
- Assess the parent’s support network and encourage them to utilize it

How Can We Help?

- Empower parents to be advocates
- Foster the parent’s skills through guided participation
  - Be an expert, coach, and facilitator
- Provide consistent communication (when parents are ready!)
  - Repeat information frequently
- Continuity of care whenever possible

Don’t Forget About Self-Care

- Nurses/health professionals are at risk for compassion fatigue and/or burnout
- Be aware of the signs and symptoms
- Important self-care strategies:
  - Maintain balance between professional and personal
  - Obtain enough sleep, exercise, and nutrition
  - Permit time for grieving for patients
  - Utilize coping skills
  - Seek help when needed (e.g., peer consultation/support, psychotherapy)
  - Consider support groups

(Reck, 2011)