Pediatric medical traumatic stress and its on impact on families

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Workshop on Ensuring Quality and Accessible Care for Children with Disabilities and Complex Health and Educational Needs
National Academies of Sciences Engineering Medicine
December 2015
Thanks to the many multidisciplinary team members who have contributed to this work over the past 20+ years. Special appreciation to the children and families who have generously participated in our studies and programs.

The research described in this presentation has been supported by the National Cancer Institute (NCI; R01CA88828, R01CA63930, R21CA98039), St Baldrick’s Foundation, American Cancer Society (RSG-13-015), the Substance Abuse and Mental Health Services Administration (SAMHSA; U79SM058139 U79SM54325) and the Nemours Center for Healthcare Delivery Science.

I have no financial disclosures related to this work.
Family/systems and social context

• Children live and interact in families (or other systems) and these systems influence every aspect of their lives
• Pediatric healthcare is family oriented...delivering care without considering the family would be naïve
• Families are the key to participatory research, patient engagement and outcomes
A social ecological approach to child health

Children live in families, and families within broader social contexts – pediatric healthcare is but one (key) system.
Family psychosocial adjustment – themes from the literature

• Children have expected, developmentally routed, emotional reactions (anxiety, depression, behavior problems)
• Mothers and fathers (caregivers) have a range of reactions, including traumatic stress responses
• Siblings are impacted (positive/negative)
• There is often a trajectory of improved functioning
• Pre-illness functioning predicts longer-term outcomes
• Social isolation is a predictor of worse outcomes
• Conditions that impact the central nervous system are associated with neurocognitive & psychosocial difficulties
An important message
The majority of children and families are resilient, but many have psychosocial concerns that can impact the course of treatment.
Medical traumatic stress

“a set of psychological and physiological responses of children and their families to pain, injury, medical procedures, and invasive or frightening treatment experiences”

Stress v. traumatic stress v. diagnosis

- Many aspects of illness and injury are stressful
- Some aspects are potentially traumatic
- Traumatic stress and associated emotional reactions can have effects that seriously impair the child’s (or family members’) functioning
- PTSS: symptoms that result in distress and may impair certain aspects of functioning
  - Re-experiencing
  - Arousal
  - Avoidance
- PTSD: Diagnosis of psychopathology
- PTSS ≠ PTSS (each is interesting)
Why might medical events lead to traumatic stress?

- Challenges beliefs about the world as a safe place
- Realistic (or subjective) sense of life threat
- High-tech, intense medical treatment may be frightening
- Child or parent may feel helpless
- Uncertainty about course and outcome
- Often involves pain or observed pain
- Exposure to injury or death of others
- Parents/family may have to make important decisions in times of great distress
## Risk factors for PTSD after acute trauma: Four meta-analyses

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subjective life threat</td>
<td>Medium to large</td>
</tr>
<tr>
<td>Child: Acute PTS symptoms</td>
<td>Large</td>
</tr>
<tr>
<td>Child: Depression, anxiety symptoms</td>
<td>Large</td>
</tr>
<tr>
<td>Parent: Acute PTS symptoms</td>
<td>Medium to large</td>
</tr>
<tr>
<td>Low social support post-trauma</td>
<td>Medium to large</td>
</tr>
<tr>
<td>Maladaptive coping strategies: social withdrawal, avoidance / thought suppression</td>
<td>Medium to large</td>
</tr>
</tbody>
</table>

Alisic, 2011; Cox, 2008; Kahana, 2006; Trickey, 2012
Evidence for PTSD/PTSS in childhood cancer

• Very common at diagnosis and during early treatment (40-50% of parents qualify for ASD)
• Continues in long-term survival - mothers and fathers of childhood cancer survivors have elevated rates of PTSS compared to controls
• Adolescent survivors are not different from controls in PTSS
• More PTSS is seen in young adult survivors
• Siblings have higher rates of PTSS than controls
• Nearly all families have at least one member who meets one of the diagnostic criteria for PTSD
## Childhood cancer long-term survivors: Specific symptoms of PTSS/PTSD

<table>
<thead>
<tr>
<th></th>
<th>Moms ¹</th>
<th>Dads ¹</th>
<th>Survivors ¹</th>
<th>Young Adults ²</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N</strong></td>
<td>146</td>
<td>106</td>
<td>150</td>
<td>78</td>
</tr>
<tr>
<td>Re-experiencing</td>
<td>97%</td>
<td>87%</td>
<td>73%</td>
<td>80%</td>
</tr>
<tr>
<td>Avoidance</td>
<td>34%</td>
<td>16%</td>
<td>16%</td>
<td>44%</td>
</tr>
<tr>
<td>D (Arousal)</td>
<td>64%</td>
<td>44%</td>
<td>41%</td>
<td>42%</td>
</tr>
<tr>
<td>PTSD Current</td>
<td>14%</td>
<td>10%</td>
<td>5%</td>
<td>18%</td>
</tr>
<tr>
<td>PTSD Since Cancer</td>
<td>30%</td>
<td>12%</td>
<td>8%</td>
<td>21%</td>
</tr>
</tbody>
</table>

¹Kazak et al., (2004); ²Hobbie et al., (2000)
PTSS/PTSD in pediatric illness

- PTSS rates consistent across transplant (solid organ, bone marrow), HIV or sickle cell disease for patients (15-18%) and parents (11-18%)
- PTSD and PTSS more prevalent in parents of cancer patients but strong evidence in injury and type 1 diabetes
- Meta-analysis of PTSD in parents and youth with cancer, T1D, epilepsy, asthma, solid organ transplant). PTSD in both mothers and fathers was 23% (20% in mothers, 12% in fathers)
Medical Events

I. Peri-trauma

II. Medical Treatment of Initial Pediatric Illness/Injury

III. Stabilization of Pediatric Illness/Injury

Key Risk Factor for Traumatic Stress

Subjective reactions and appraisals of medical event(s)

Family Traumatic Stress Symptoms
Patient caregiver sibling

Assessment & Intervention Implications

Trauma-Informed Care & Screen for Risk

Screen for Risk, Prevent Traumatic Stress, Treat Significant Traumatic Stress

Screen for Risk, Treat Significant Traumatic Stress

Time

Pediatric Psychosocial Preventive Health Model

ADDRESSING TRAUMATIC STRESS IN THE PEDIATRIC HEALTHCARE SETTING

CLINICAL/TREATMENT
- Consult behavioral health specialist.
- Intensify psychosocial services.
- Address impact on medical treatment.

TARGETED
- Monitor child/family distress and risk factors.
- Provide interventions specific to symptoms or adherence needs.

UNIVERSAL
- Provide psychoeducation and family-centered support.
- Screen for indicators of higher risk.

Severe, escalating, or persistent distress.
Acute or elevated distress. Other risk factors present.
Children and families are distressed but resilient.

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Brief parent-report screen of psychosocial risk in pediatric healthcare

All literacy English and Spanish versions (4th grade reading level)

Available in English, Spanish (US, S. American), Dutch, Portuguese, Hebrew, Greek, Polish, Italian, Japanese, Chinese/Mandarin, Korean, Swahili, Hindi, Czech and adaptations for the UK, Singapore, Canada and Australia, New Zealand

Used in research and clinical care at 77 U.S. sites/33 states since 2007 (approximately 6,500 administrations) and 30 international sites

Adaptations

- Kidney transplant
- NICU/CICU
- Inflammatory bowel disease
- Sickle cell
- Weight management#
- Bone marrow transplant#
- Diabetes
- Chronic liver disease
- Solid organ transplant
- Disorders of sexual development
- Fetal myelomingocele
- Aplastic anemia
- International adoption
- PACU
- Rehabilitation
- Chronic pain
- Kinship care
- Chronic migraine
- Cardiology
- Prader-Willi
- PICU
- Craniofacial
- Severe combined immunodeficiency
- Burns

Subscales

- Structure/Resources
- Family Problems
- Social support
- Stress reactions
- Child problems
- Sibling Problems
- Family beliefs
PAT family psychosocial risk screening

Immediate risk scoring and family-centered reports to support decision making and communication

Immediate risk scoring and reports to provider via EPIC
Support for the PPPHM

Percent of families at each risk level (as measured by the Psychosocial Assessment Tool)

All US PAT Users  N = 6,479

- 55% Universal
- 34% Targeted
- 11% Clinical

N = 6,479
### Sample Interventions by Risk Level

<table>
<thead>
<tr>
<th>Risk Level</th>
<th>Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinical</strong></td>
<td><strong>Severe, escalating problems</strong></td>
</tr>
<tr>
<td><strong>Targeted</strong></td>
<td><strong>Supportive counseling – intensive</strong></td>
</tr>
<tr>
<td><strong>Universal</strong></td>
<td><strong>Psychosocial Education</strong></td>
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</table>
Basics of Trauma-Informed Care

**REDUCE DISTRESS**
- Ask about fears and worries.

**EMOTIONAL SUPPORT**
- Who and what does the patient need now?

**REMEMBER THE FAMILY**
- Gauge family stressors and resources.

How Providers Make a Difference

Healthcare providers are experts in treating illness and saving lives. After attending to the basics of physical health (A-B-C: Airway, Breathing, Circulation), you can promote psychosocial recovery by paying attention to the D-E-F (Distress, Emotional Support, Family).

What is Trauma-Informed Pediatric Care?
Trauma-informed pediatric care means incorporating an awareness of the impact of traumatic stress on ill or injured children and families as a part of treating the whole patient.
Continuing education for nurses on how to integrate the D-E-F in practice

D is for Distress: Helping pediatric patients with pain, fear, and worries

What would you do? Click an option to see what happens next

- Assess Anthony’s pain to see if it has changed. Consider talking with attending physician about optimizing pain management.
- Let Anthony know that lots of kids have trouble sleeping in the hospital – it’s different from home and they might be worried about something.
- Do nothing right now – he is probably sleepy and needs some time alone to try to rest. Make a note in the chart for social work to talk with Anthony later.

Recap from Anthony’s story: Pointers for assessing distress

Pain
Use your hospital’s pediatric pain assessment.
- Ask: How has your pain been since this happened / since you’ve been in the hospital?
- Ask: How is your pain right now?
- Ask: Is it getting better, getting worse, about the same?

Fears and worries
- Say: Sometimes kids get worried about things when they have to be in the hospital.
- Ask: What has been scary for you?
- Ask: What worries you the most right now?

Enroll at www.healthcaretoolbox.org
For more information:
www.healthcaretoolbox.org
Anne.Kazak@nemours.org

WHAT WE KNOW
- 20-30% of children and their parents who experience life changing illness or injury develop symptoms of Post-Traumatic Stress Disorder (PTSD).
- 25% of siblings develop moderate to severe symptoms of PTSD.
- Research shows trauma can be minimized and outcomes improved through experiences that reduce stress.

HELP IS HERE!
YOU ARE NOT ALONE.
Child life, social work and psychology departments at your hospital can help.

YOU ARE NOT HELPLESS.
Research shows that dealing with the stress of this experience now can minimize PTSD for everyone in the future.

SUPPORT IS A CLICK AWAY.
Helpful tools, tips and resources for coping are available at www.careforfamilies.org/copings.

GET INVOLVED!
For details! Check out:
http://careforfamilies.org/get-involved/

Traumatic Stress in Ill or Injured Children
AFTER THE ABC’S CONSIDER THE DEF’S

D  Distress
• Assess and manage pain.
• Ask about fears and worries.
• Consider grief and loss.

E  Emotional Support
• Who and what does the patient need now?
• Barriers to mobilizing existing supports?

F  Family
• Assess parents’ or siblings’ and others’ distress.
• Gauge family stressors and resources
• Address other needs (beyond medical)