

Pediatric Medical Traumatic Stress

Identification, Prevention and Treatment in Pediatric Oncology

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No Conflicts of Interest to Disclose

Presentation Overview

Part 1: Understanding pediatric medical traumatic stress

- Child and parent medical experiences
- Traumatic stress symptoms
- Risk factors for traumatic stress responses:
 - Developmental issues
 - Role of beliefs

Part 2: Opportunities for prevention and intervention

- Trauma-Informed Pediatric Care
 - Integrating family-centered and trauma-informed care
 - Responding to traumatic stress: PMTS Toolkit and D-E-F Protocol
- Intervention strategies along the continuum of care



Presentation Overview



Responses to Medical Trauma

- When facing serious illness or injury many pediatric patients and their families are able to cope well, with the basic supportive interventions and with time.
- Some may develop persistent traumatic stress reactions, such as posttraumatic stress disorder, which impedes both physical and psychosocial health-related quality of life.
- As pediatric health care providers, you have an opportunity to make a difference in how children and their families experience serious illness and injury, and the medical care they receive.

Responses to Medical Trauma

Impact of Medical Traumatic Stress

- Up to 80% of children and their families experience some traumatic stress reactions following life-threatening illness, injury or painful medical procedures.
- 20-30% of parents and 15-25% of child patients and siblings experience persistent traumatic stress reactions.
- When they persist, traumatic stress reactions can:
 - Impair day-to-day functioning
 - Reduce adherence to medical treatment
 - Impede optimal recovery from injury or illness
 - Undermine relationships between providers and patients

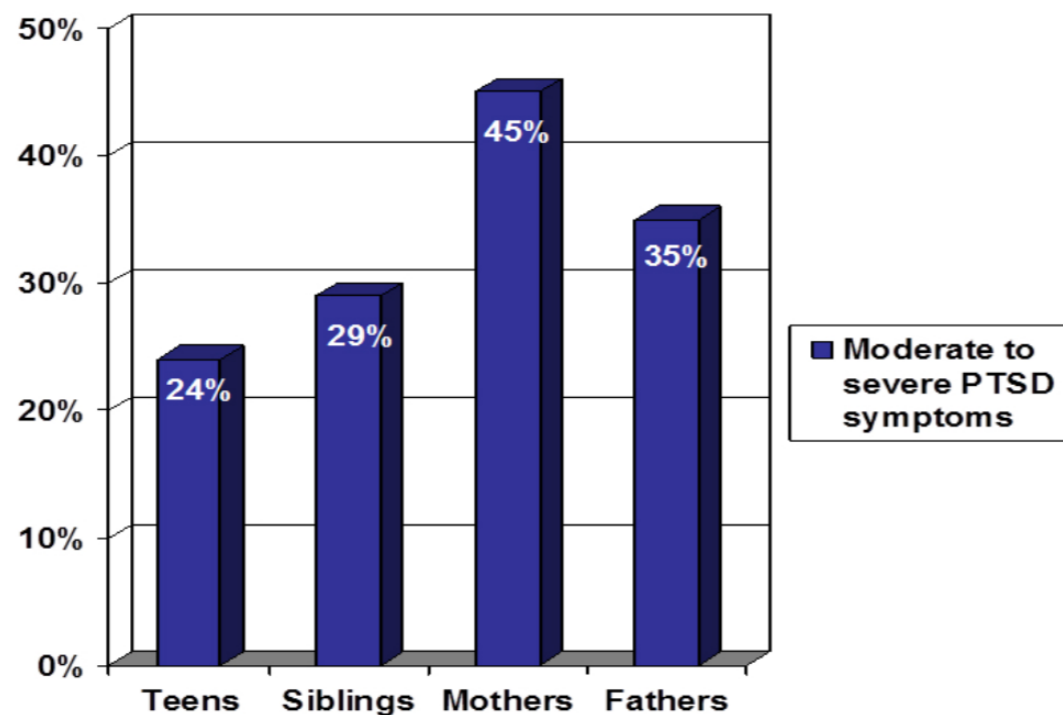
Impact of Medical Traumatic Stress

<i>Sample / Setting</i>	<i>Patients</i>	<i>Rate Reported</i>	<i>Parents</i>	<i>Rate Reported</i>
<i>Illness:</i>				
Cancer: In-Treatment	√	~10%	√	23-71%
Cancer: Survivors	√	12-52%	√	20-43%
Cardiac Surgery	√	24-29%	√	~16%
Organ Transplantation	√	11-29%	√	27-58%
HIV	√	~33%		
Asthma	√	11-20%	√	14-29%
Diabetes	√	~5%	√	20-46%
Epilepsy			√	~31%
<i>Injury:</i>				
Burns	√	6-53%	√	12-37%
Motor Vehicle / Pedestrian	√	12-55%	√	3-15%
Traumatic Brain Injury	√	21-49%		
Spinal Cord	√	25-46%	√	~53%
Disfigurement	√	21%		
<i>Intensive Care:</i>				
PICU	√	21-48%	√	13-27%

Pediatric Cancer: clinically significant PTS symptoms

In families facing childhood cancer, rates of PTSD are often higher in parents than in the child with the cancer.

Symptoms in families of teen cancer survivors one year or more post-treatment



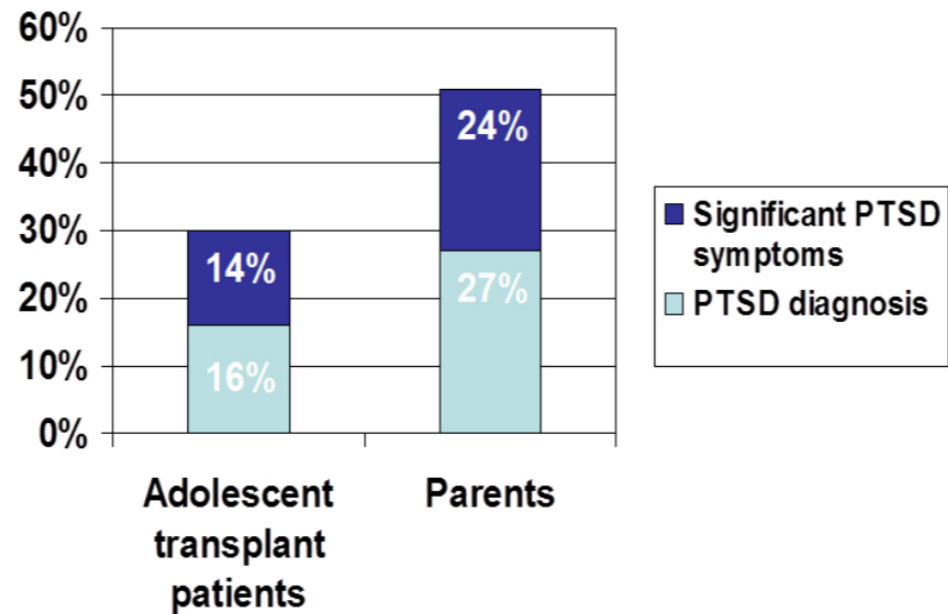
Kazak et al. (2004). Posttraumatic stress symptom and posttraumatic stress disorder in families of adolescent cancer survivors. *Journal of Pediatric Psychology*.

Pediatric Cancer: clinically significant PTS symptoms

Pediatric Transplant: clinically significant PTS symptoms

Pediatric Transplant: clinically significant PTS symptoms

Symptoms in 104 adolescent transplant patients (age 12 to 20) and their parents more than one year post-transplant.



Mintzer et al. (2005). Traumatic stress symptoms in adolescent organ transplant recipients. *Pediatrics*.

What is Traumatic in Medical Experiences?

- **It's not just the time of diagnosis or accident.**
 - Traumatic stressors, reminders, and losses occur at various times during treatment - even after treatment ends.
- **Trauma challenges our beliefs and assumptions.**
 - About safety, vulnerability, and the “natural order” of things.
 - Parental beliefs (“I should have taken him/her to the doctor sooner”) can be especially challenging.
- **Sometimes the “cure” (treatment) is equally traumatic to the diagnosis.**
 - Painful treatment, hair loss, chemotherapy, surgical scarring are often perceived by children as more traumatic than the illness or injury itself.



What is Traumatic in Medical Experiences?

What is Traumatic? (cont'd)

- **Making decisions under duress.**
 - In medical environments, the family is often required to make important decisions under duress, with potentially uncertain outcomes.
- **Continued exposure can prolong the trauma.**
 - Hospitalized children and families are continually exposed to seeing other sick or injured children, or knowing children who died.
- **At times, there is no definite end to the traumatic situation.**
 - Ongoing treatment and uncertain outcome / prognosis maintain trauma threat.
 - Late effects of treatment, occurring years after treatment ends, can re-traumatize patients and families.



What is Traumatic? (cont'd.)

What is Traumatic for Children?

- Being left alone
- Being in pain or painful procedures
- Having a noticeable injury / disability
- Exposure to medical equipment that is frightening
- Fearing what other children will think of them
- Uncertainty about what will happen next
- Seeing other hurt or sick children
- Thinking that the illness/injury is punishment for something they did wrong
- Fear of dying



What is Traumatic for Children?

What is Traumatic for Parents?

- The specific period surrounding the diagnosis or life-threatening injury
- Ongoing uncertainty regarding prognosis
- Treatment setbacks or relapse
- Feeling helpless or guilty
- Fear of their child dying
- Exposure to other parents' distress, or to death of other patients
- Seeing their child in pain, going through invasive procedures, or hooked up to medical equipment



What is Traumatic for Parents?

In their own words... children and parents

“I thought I was going to die. I thought I must really be hurt. ...I was so scared because my mom was not there.”

“We went from taking him to our family doctor, thinking that he had some kind of flu, to by the end of the afternoon being in the ICU and having him inundated with needles, and tubes, and ...

Wow! How did the day end up like this?”

“It all happened so quickly. I was ‘out of it’ and in pain. I was given the first chemo treatment without being told what was going on – that upset me for a long time after that.”

“I saw my son lying on the stretcher, crying, the ambulance, everybody around him. ...It was a horrible scene. I thought I was dreaming.”



In their own words...



What is 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.”

National Child Traumatic Stress Network, 2003



What is Medical Traumatic Stress?

Defining Medical Traumatic Stress

Medical traumatic stress responses:

- are related to subjective experience of the event
- vary in intensity
- can become disruptive to functioning
- hallmark symptoms include re-experiencing, avoidance, arousal and sometimes, dissociation

Defining Medical Traumatic Stress

Traumatic Stress Symptoms

Re-experiencing

- Thinking a lot about the injury, illness, or medical procedure (unwanted and intrusive).
- Feeling distressed at thoughts or reminders.
- Having nightmares, flashbacks.
- “It keeps popping into my mind.”
- “It feels like it’s happening all over again.”
- “I get upset when something reminds me of it.”

Traumatic Stress Symptoms

Traumatic Stress Symptoms

Avoidance

- Not wanting to think / talk about the injury, illness, or hospital experience.
- Avoiding reminders or triggers.
- Missing or canceling appointments or therapeutic activities, medication non-compliance.
- Displaying less interest in usual activities.
- Feeling emotionally numb or detached from others.
- “I block it out – and try not to think about it.”
- “I try to stay away from things that remind me of it.”

Traumatic Stress Symptoms

Traumatic Stress Symptoms

Increased Arousal

- Increased irritability, agitation.
- Acting out behavior.
- Trouble concentrating or sleeping.
- Exaggerated startle response.
- Hyper-vigilance / overprotection.
- “I am always afraid something bad will happen.”
- “I get jumpy at any loud noise.”
- “I cannot concentrate / can't sleep.”



Traumatic Stress Symptoms

Traumatic Stress Symptoms

Dissociation

- Feeling in a daze or spacey.
- “It felt unreal-like I was dreaming.”
- “I can’t even remember parts of it.”

Other Feelings

- New fears.
- Somatic complaints not explained by a medical condition or treatments.



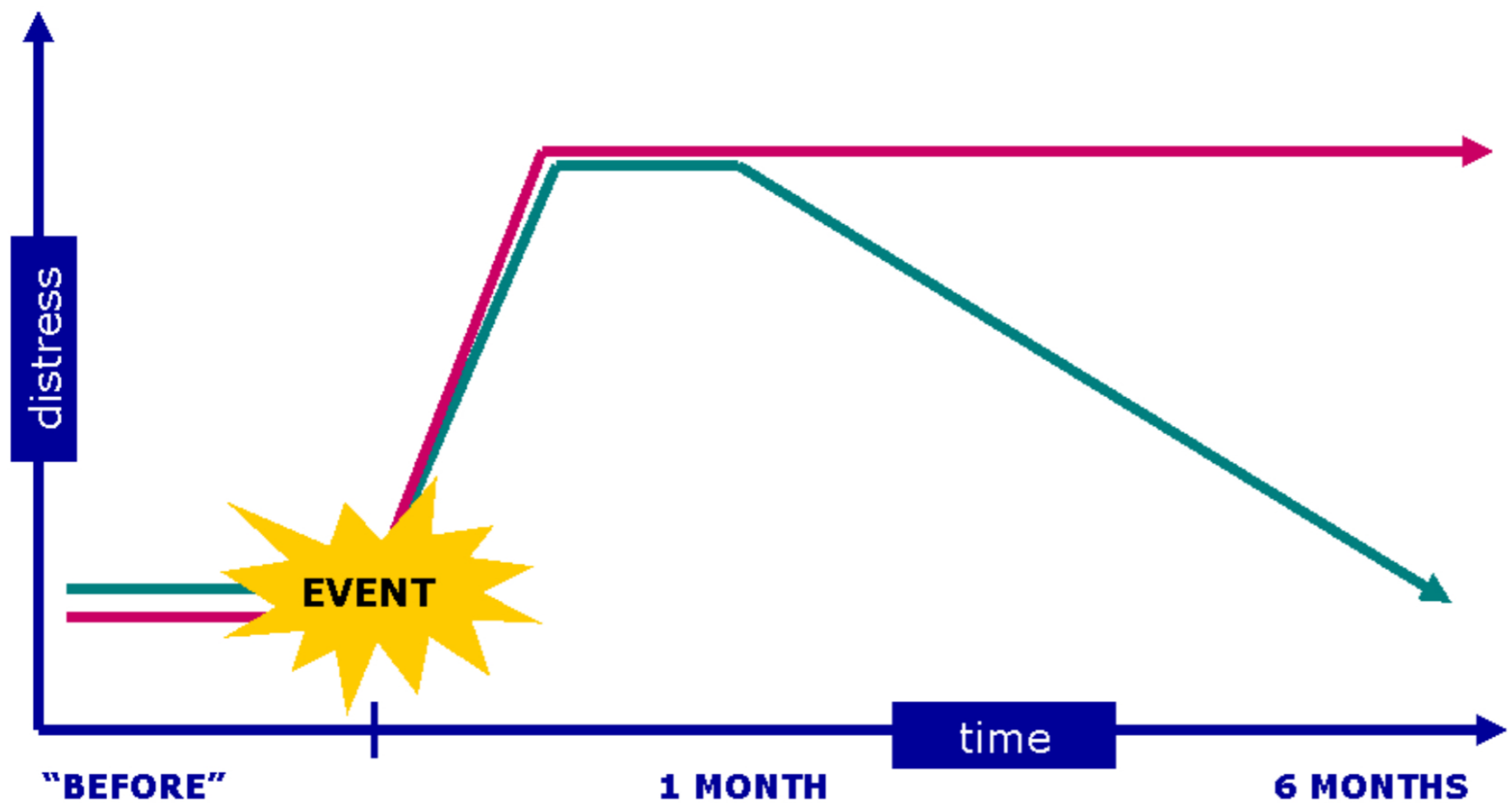
Traumatic Stress Symptoms



Trajectory of Traumatic Stress

- Initial distress in health care settings is common, expected, and understandable.
- Many children and parents cope well with the basic supportive interventions and with time.
- Some may develop persistent traumatic stress reactions, such as posttraumatic stress disorder, which impede both physical and psychosocial quality of life.



Trajectory of Traumatic Stress



-  Shows normal coping
-  Shows traumatic stress reactions

Navigation icons: a person icon, a play button, and a large play button.

Risk Factors for PTS in Cancer

Before diagnosis

- Prior traumatic experiences or prior posttraumatic stress.
- Prior anxiety or behavioral or emotional issues.

At diagnosis

- Concurrent stressors.
- Painful or frightening procedures and treatments.
- Worry about dying.

During treatment / remission

- Feeling isolated or different from peers.
- Painful treatments or frightening procedures.
- Maladaptive coping and social isolation.
- Lacking social supports or coping resources.



Risk Factors for PTS in Cancer

Risk Factors for PTSD (cont.)



- Studies of injured children showed that neither acute stress nor posttraumatic stress responses were associated with objective measures of severity of injury or illness. Rather they were associated with subjective feelings about the situation (Balluffi et al., 2004; Winston et al., 2008).
- Implication: Not only the most ill or injured children need extra attention.



Risk Factors for PTSD (cont'd)

Risk Factors: Children

No. 1: Child's subjective perception of life-threat (often unrelated to objective prognosis)

- Children who are afraid that they might die can have more significant traumatic stress responses.
- Medical providers' objective perceptions of diagnosis and prognosis can be quite different from what child is thinking / feeling.
- Children will not necessarily tell providers that they are worried about dying.



Risk Factors: Children



Other Risk Factors: Children

- Severe pain and/or painful treatment
- Separation from parents / caregivers
- Previous history of other trauma (medical / non-medical)
- Prior behavioral / emotional problems
- Lack of peer support
- Acute traumatic stress reactions



Other Risk Factors: Children

Risk Factors: Parents / Caregivers

- Subjective perception of life-threat to child, regardless of diagnosis / prognosis
- Parents' trauma history
- Prior emotional / mental health problems
- Experiencing concurrent losses, life stressors, or disruption
- Lack of social support

Risk Factors: Parents/Caregivers

Developmental Issues and Traumatic Stress: Young Children

Responses are more behavioral

- will SHOW you that they are upset, rather than tell you.

Can regress behaviorally

- including bed wetting, thumb sucking, being more clingy with caregivers etc.

Cannot self-soothe

- show strong startle responses, have nightmares and emotional outbursts as a result.

Think in images

- are more likely to process trauma through play, drawing, or storytelling.



Developmental Issues and Traumatic Stress: Young Children

Developmental Issues and Traumatic Stress: School-Age Children

Will take cues from adults' non-verbal behaviors

- will discount verbal explanations if what they observe does not match up with what they are told.

Will use their active imaginations

- to fill in the blanks when they do not have realistic and accurate information or explanations.

Can believe that an illness or injury is punishment

- for something they said, thought, or did wrong.

Can experience significant grief and loss reactions

- even if expected and prepared for.



Developmental Issues and Traumatic Stress: School-Age Children

Developmental Issues and Traumatic Stress: Adolescents

Are more concerned with the “here and now”

- future is too abstract; view themselves in concrete terms.

Can be idealistic

- or unrealistic in expectations for themselves and others.

Are self-conscious

- and sensitive about looking different than peers.

Can act more grown up than they feel inside

- to protect others from their thoughts and feelings.

May resent feeling dependent

- on parents and providers.

Developmental Issues and Traumatic Stress:
Adolescents

Questions?

Feel free to call:
267-426-8135



[Continue to Part Two](#)



Questions?

