Pediatric Medical Traumatic Stress

Identification, Prevention and Treatment in Pediatric Oncology

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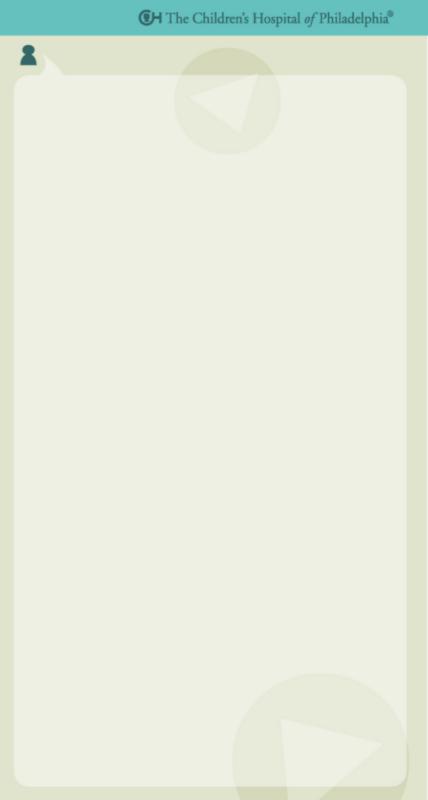
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Part 2: Prevention and Intervention



Intervention Models: Medical Traumatic Stress

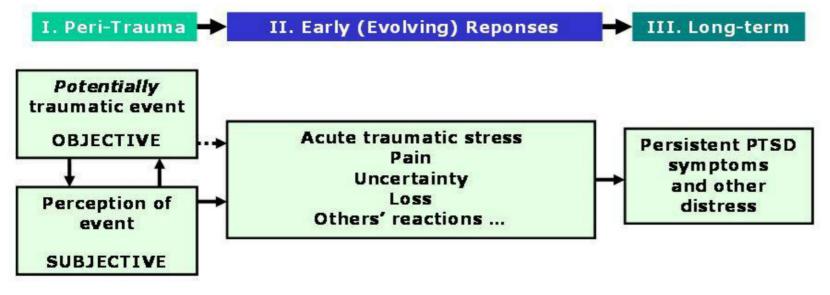
- Phases of Medical Traumatic Stress Model
 - Matches potential interventions to different stages of traumatic stress development.
- Prevention and Treatment Model
 - Stratifies children and families into three levels of intervention based on early symptoms.
- Family-centered and Trauma-informed Care



Intervention Models: Medical Traumatic Stress



Three stages of response.....



... with different implications for intervention.

Address child's experience of event

Address immediate needs Reduce distress Prevent PTSD symptoms

Treat PTSD & other ongoing distress



Phases of medical traumatic stress

^{*}Kazak, A., Kassam-Adams, N., Schneider, S., Alderfer, M., Zelikovsky, N., & Rourke, M. (2006). An integrative model of pediatric medical traumatic stress. <u>Journal of Pediatric Psychology</u>.



Phases Model — Phase I

Phases Model—Phase I

Peri-Trauma

- Initial events, or trauma events that are still unfolding:
 - in the midst of emergency care
 - during injury event
 - during diagnosis of a serious illness
- Intervention focus is on reducing the traumatic aspects of this experience for children both objective and subjective.
- Provide anticipatory guidance about what to expect, what's "normal" and helpful ways of coping.



Phases Model — Phase II

Phases Model—Phase II

Phase II: Early, ongoing, evolving responses

- The days and weeks that follow the traumatic event.
- Intervention focus is on promoting adaptive coping and addressing immediate distress.
- Screen for acute distress and risk factors to determine which children and families might need more support.
 - Practice "watchful waiting" with those less distressed.
 - Help strengthen coping skills
 - Reframe unhelpful beliefs
 - Provide referrals as needed for those with significant distress.

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Phases Model — Phase III

Phases Model—Phase III

Longer Term Posttraumatic Stress Symptoms

- Months or years after a traumatic event, illness or injury.
- Intervention focus is on supporting adaptive coping, detecting persistent stress reactions, and referring for further mental health treatment.
- Identify coping needs and promote family and community / religious support.

Prevention Model:

Addressing traumatic stress in the pediatric healthcare setting

Clinical / Treatment

Acute distress or a few risk factors present.

Arrange psychosocial

and mental health support.

Persistent distress or risk factors.

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Provide extra support and anticipatory guidance. Monitor ongoing distress and refer if needed.

Targeted

Most children and families are understandably distressed but coping well.



Universal

Provide general support — help family help themselves.

Provide information regarding common reactions. Screen for indicators of higher risk.



Prevention Model

2

Prevention Model: Levels of Symptoms

Prevention Model: Levels of Symptoms

- Universal- Some distress, but most children and families have coping strengths and resources.
- Targeted- Acute distress or risk factors present; child / family does not appear to have strong coping resources; other concurrent (non-medical) stressors are present.
- Clinical and Treatment- significant distress, multiple risk factors, few coping strengths, and/or posttraumatic stress symptoms (PTSS).

Universal Preventive Interventions

For: Children and families are distressed but resilient; who have coping strengths and resources:

- Help families help themselves
 - Provide general support
 - Provide psychoeducation
 - Screen for indicators of risk
- Employ "watchful waiting" for first few days/weeks to see if distress abates.
- Use DEF protocol
 - Reduce Distress
 - Provide Emotional Support
 - Remember (and include) the Family



Universal Preventive Interventions

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Universal Preventive Interventions, cont'd.

Universal Preventive Interventions (cont'd)

Provide Trauma-informed Care

- Minimize potential traumatic medical experiences (sights, sounds, smells, procedures) inpatient and outpatient
- Anticipate and address distress and common traumatic stress reactions.
- Screen to determine who needs additional support.
- Identify family needs and strengths.

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Targeted Interventions

Targeted Interventions

For: Children and families with acute distress, who have additional risk factors, and/or have few coping strengths and resources:

- Provide interventions specific to symptoms, coping needs, and beliefs.
- Continue use of DEF protocol and Trauma-Informed care.
- Monitor distress level and refer to mental health provider if symptoms or get worse.
- An example of an effective universal / targeted intervention is The Cellie Cancer Coping Kit.

The Cellie Cancer Coping Kit

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The Children's Hospital of Philadelphia has filed a provisional patent for the kit and may benefit financially from the kit.

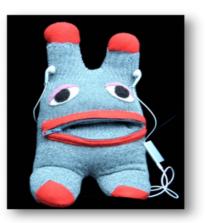


The Cellie Cancer Coping Kit



Develop a tool which is:

- Evidence-based
- Low cost
- Easy to implement without a mental health provider
- Available at the time the child needs it
- Specific to the experience of the medical event(s) and related treatment
- Developmentally sensitive for children ages 6-12
- Engaging to families
- Possible to integrate into standard physical care





Cellie Program Objectives





Cellie Cancer Coping Kit



Topics

- Communication about cancer
- Appointments & procedures
- Treatment side effects
- Adjusting to treatment
- School and friends

Book only

Challenges concerning the whole family



Coping Cards & Caregiver Book

Coping Card Example:

I don't like needle sticks/port access/spinal taps

Sample Strategies:

- Make a plan with your parents and your nurse. Your plan could include:
 - Squeeze a stress ball before you get poked for a blood draw.
 - Listening to music (make a playlist only for pokes) or play video games
 - Squeezing Cellie tight and looking at Cellie until it is over
- Ask your nurse or child life specialist to give Cellie an IV or blood draw.





Coping Card Example

Research Results

- 100% families used the Cellie Coping Kit
- Families used the Cellie Kit:
 - For psychoeducation and/or to learn new ideas for coping
 - To normalize experiences
 - To gather information
 - To initiate conversations
 - For fun
 - To promote emotional expression
 - For general comfort





Research Results



Families reported learning:

- New coping techniques (e.g., breathing, distraction, talking to parents)
- Common reactions and experiences for families facing pediatric cancer
- Ways to promote communication about cancer within the family
- Provided approximately 150 unique tips not mentioned by families





Research Results, cont'd.

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Research Results, cont'd.

Research Results

SAMPLE COMMENTS

PARENTS

"[My daughter] is very attached (to Cellie)... [she uses it] at night to go to sleep and definitely for the chemo every week and generally [for when she's] feeling sad or tired." "[I use the Kit] when I'm not feeling well... I look through it and try to see if there are any cards that could help and see

what I could do... and I try it. "

CHILDREN

"We reviewed the cards and [helped]
him understand that some of the
feelings he has are similar to [other]
children here... so he didn't feel like he
was alone."

"I sleep with Cellie. I keep her with me when I'm getting the needle in. Cellie's the bomb... it helps me a lot."



Clinical (Treatment) Interventions

Clinical (Treatment) Interventions

For: children and families with significant or worsening distress, posttraumatic stress symptoms, multiple risk factors, and few/no coping strengths or resources

- Consult behavioral health specialist for assessment
- Refer for further mental health treatment



FAMILY-CENTERED CARE

TRAUMA-INFORMED CARE

- Focus on dignity & respect for patient / family
- Maximize family involvement in care
- Respect patient / family wishes for interdependence & privacy

- Integrated in every patient interaction
- Share information with patient and family
- Encourage family presence
- Recognize family strengths & needs
- Cultural competence

- Minimize potential for trauma during medical care
- Address distress
- Promote emotional support
- Encourage return to daily activities when possible



Elements of family-centered and trauma-informed pediatric care

Remember D-E-F Protocol for Trauma-Informed Care

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)?



Remember D-E-F Protocol



How to Assess: Distress

TRAUMATIC STRESS IN ILL OR INJURED CHILDREN

Pain. Use your hospital's pediatric pain assessment. Ask:

- How is your pain right now?
- What was your worst pain since this happened?

Fears and worries, Ask:

- Sometimes, kids get upset when something like this happens.
 What has been scary or upsetting for you?
- What worries you the most?

Grief or loss, Ask:

- · Was anyone else hurt or ill?
- · Have you had other recent losses? (home, pet, etc.)



How to Help: Distress

TIPS TO HELP FAMILIES OF INJURED OR ILL CHILDREN

1 Provide child with as much control as possible.

- · Help the child understand what is happening.
- · Allow the child to have a say in what will happen next.

2 Actively assess and treat the child's pain.

- · Use your hospital's pain management protocol.
- Teach child and parent basic coping techniques.

■ Provide accurate information, using basic words.

- · Ask the child to repeat back explanations.
- · Listen carefully and clarify misconceptions.

4 Provide reassurance and realistic hope.

- Describe what is being done to help the child feel better.
- · Address the child's concerns or worries.



Distress

A

Emotional Support

Emotional Support

O How to Assess: Emotional Support

TRAUMATIC STRESS IN ILL OR INJURED CHILDREN

What does the child need now?

- Parents: What helps your child cope when upset/scared?
- Child: What helps you feel better when you are upset/scared?

Who is available to help the child?

- Do parents understand the illness/injury or treatment?
- Can they be with their child during procedures?
- Can they help calm/soothe their child?

What are the barriers to mobilizing parent support?

- Do parents' responses make it harder for them to help?
- · How confident is the parent in caring for the child?



How to Help: Emotional Support

TIPS TO HELP FAMILIES OF INJURED OR ILL CHILDREN

■ Listen to parents and encourage their presence.

- · Ask parents for their expertise about their child.
- Ask parents about their concerns.
- . Encourage them to be with their child.

Empower parents to help their child.

- Suggest ways they can help their child.
- Involve them in physical care, as appropriate.
- Help them seek out support if upset/anxious.

Encourage child/parent involvement in "normal" activities.

- Suggest activities that fit the child's medical status.
- Find activities that the child and parent can do together.
- Promote contact with the child's friends and teachers.



Family

O How to Assess: Family

TRAUMATIC STRESS IN ILL OR INJURED CHILDREN

Assess distress of parents/family members. Ask:

- How is your family coping right now?
- · Who is having an especially difficult time?

Gauge family stressors and resources. Ask:

- · Are you eating, getting sleep, and taking breaks?
- · Do you have friends who can help out at home?

Address other needs (beyond medical). Ask:

 Are there other stressors going on (such as money, job, transportation) that make it particularly difficult right now?



How to Help: Family

TIPS TO HELP FAMILIES OF INJURED OR ILL CHILDREN

■ Encourage parents' basic self-care.

- Encourage parents to sleep, eat, and take breaks.
- Help them enlist support of friends, family, and community.

2 Remember other family members' needs.

- Involve siblings and explain treatment to them when possible.
- Enlist hospital resources such as chaplain and social work as needed.

Be sensitive to the cultural and resource needs of the family.

- Remember that outside issues can impact recovery.
- Be open to involving other healing professionals and customs.



Family





Culture and Provider Self-Care

Culture and Provider Self-Care

How to Assess: Culturally Sensitive Trauma-Informed Care ...QUESTIONS PROVIDERS SHOULD ASK

LISTEN

...for variations in understanding. Ask:

- What is your understanding of what's happened?
- · What is worrying you the most?
- What does your family think about it?

BE OPEN

...to involving other professionals. Ask:

- · Who do you normally turn to for support?
- . Who else should be involved in helping your child?
- · Are you open to outside referrals and resources?

RESPECT

...different communication practices. Ask:

- · Who typically makes the decisions about your child?
- What information should be shared with your child?
- Is there anyone else you would like me to talk to?

For the Provider: Working with Traumatized **Children and Families**

· · · ABCs OF PROVIDER SELF-CARE

AWARENESS

- Be aware of how you react to stress (overworking, overeating, etc.).
- · Monitor your stressors and set limits with patients and colleagues.
- Talk to a professional if your stress affects your life or relationships.

BALANCE

- Diversify tasks and take breaks during the workday.
- Eat sensibly, exercise regularly, and get enough sleep.
- Engage in activities outside of work; use your vacation days.

- · Connect regularly with family, friends, and community.
- **CONNECTION**: Use meditation, prayer, or relaxation to connect with yourself.
 - When not at work, disconnect from professional role and e-mail. Adapted from Saakvitne & Pearlman, 1996

For More Information:

- Center for Pediatric Traumatic Stress
 The Children's Hospital of Philadelphia
 - General website: www.chop.edu/cpts
 - Training website: www.healthcaretoolbox.org
 - Email: cpts@email.chop.edu
- National Child Traumatic Stress Network:
 - Website: <u>www.nctsn.org</u>
- Pediatric Medical Traumatic Stress Toolkit (online)
 - Website: www.nctsn.org/medtoolkit



For More Information

Questions?

Feel free to call: 267-426-8135

