

The Medical Traumatic Stress Toolkit

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ABSTRACT

Children and their parents who are exposed to medical life threat due to illness or injury are at risk for developing symptoms of posttraumatic stress. However, the prevention, detection, and treatment needed are often not available in the acute care settings of the hospital. The National Child Traumatic Stress Network and the Substance Abuse and Mental Health Services Administration have created a set of materials for use by hospital health providers and families that is available for download free from the National Child Traumatic Stress Network website, www.nctsn.org.

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INTRODUCTION

Hospitals deal with pediatric trauma on a daily basis. Each year five of every 100 American children are hospitalized for a major acute or chronic illness, injury, or disability. Twenty-million children in the United States each year suffer unintentional injuries, resulting in 8.7 million emergency room visits for injury; 241,000

Needs Assessment:

Posttraumatic stress disorder is a treatable psychiatric disorder that is rarely properly identified or treated in medically ill children. Yet, it is associated with increased morbidity and even mortality. It is important to educate clinicians about the symptoms and consequences of posttraumatic stress disorder in cardiovascular patients so that adequate treatment can be provided.

Learning Objectives

At the end of this activity, the participant should be able to:

- Identify the web site from which the kit can be downloaded.
- Understand why medical illness can be emotionally traumatic.
- Understand the basic strategies to identify and treat posttraumatic stress disorder in medically ill children.

Target Audience: Neurologists and psychiatrists

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children annually are injured seriously enough to be hospitalized. One in four children receives medical attention for unintentional injuries. Over 11,000 children are diagnosed with new cancers each year in the US, and there are an estimated 250,000 children who are cancer survivors. More than 1,000 children have organ transplants each year and several thousand more are awaiting transplants. Other life-threatening or painful events or conditions, such as burns, sickle cell disease, and severe asthma, affect large groups of children, and every day children undergo painful procedures as part of necessary medical care.

Most medical staff members are aware that motor vehicle accidents, burns, near-drowning, and acute injuries requiring a trip to the emergency department or hospitalization are extremely stressful for children and their families. However, the healthcare providers in hospital settings receive little training in the acute and long-term emotional and behavioral response of children of different ages to these medical traumatic events.

Recent studies have demonstrated that serious injuries and illnesses can result in symptoms of traumatic stress, both acutely and chronically, in children and parents. Chronic symptoms were seen in a recent study of adolescent cancer survivors ≥ 1 -year post-treatment, 24% of the teens, 29% of their siblings, 45% of the mothers, and 35% of the fathers reported moderate to severe symptoms of posttraumatic stress.¹ Similarly, a study of 104 adolescent organ transplant recipients at least 1-year post-transplant and 12–20 years of age,² found that $>16\%$ of the adolescents reported symptoms consistent with a diagnosis of posttraumatic stress disorder. More acute symptoms were assessed in 243 children within 1 month after a serious injury. Eight percent of children met the symptom criteria for acute stress disorder (ASD) and another 14% had subsyndromal ASD.³ A similar study looked at 12- to 48-month-old acutely burned children to assess acute traumatic stress outcomes. Of the 52 subjects, almost 30% of these children were found to have acute stress symptoms.⁴

It could be argued that care of children in an acute care setting, like an emergency room or intensive care setting, should focus on the child's survival, and that emotional issues are secondary. What are considered the "ABCs" (airway, breathing, circulation) of emergency care must, of course, come first. However, even such care can be done in ways which are more or less traumatic

to a child. Separation from a parent, loud noises, strange equipment, can amplify the fear and pain the child is experiencing. Given that the interpretation of severity of the event is one of the chief determinants of later traumatic stress symptoms,⁵ decreasing the sense of horror, fear, and helplessness can make a large difference in the likelihood of later problems. Trauma awareness can allow prevention of some traumatic experiences, recognition of traumatic responses, and intervention for children in distress.

BACKGROUND

In 2001, the United States Congress created the Donald J. Cohen National Child Traumatic Stress Initiative, a series of grants totaling $>\$30$ million. These funds were to be used improve access to care, treatment, and services for children and adolescents who have been exposed to traumatic events and to encourage and promote collaboration between service providers in the field. The centerpiece of this initiative is the National Child Traumatic Stress Network (NCTSN), established through grants awarded by the Center for Mental Health Services (CMHS) of the Substance Abuse Mental Health Services Administration (SAMSHA), US Department of Health and Human Services. The network, currently comprised of 54 centers spread across the US, addresses all types of childhood trauma. Two of the centers have a specific focus on medical traumatic stress, Children's Hospital of Philadelphia and Boston Medical Center, but many other centers within the network have an interest in working with children who are seen in hospital settings.

In 2003, a Working Group came together from Network centers across the country, to brainstorm on the needs of hospitals helping children and parents during and after a medically traumatic event. Each member of the Working Group was a clinician with a concern and experience with children coping with life-threatening illnesses or injuries. The group included pediatricians, intensive care specialists, psychologists, psychiatrists, nurses, social workers, and educators. All were interested in how to promote prevention, recognition, and interventions for traumatic stress symptoms in children in a hospital setting. Although there was considerable concern expressed about children seen in primary care settings, the hospital, with its acute life-and-death situations, and with its frequent invasive and/or painful treatments, appeared the

best place to start an intervention.

Through multi-site collaboration, and with additional funding from SAMHSA, a Medical Traumatic Stress Toolkit for Health Care Providers was created. The goals of the Pediatric Medical Traumatic Stress Toolkit for Health Care Providers are to: Raise awareness among health care providers about traumatic stress associated with pediatric medical events and medical treatment and how it may affect children and families; promote "trauma-informed practice" of pediatric health care in hospital settings across the continuum of care and in a variety of settings within the hospital (eg, from emergency care to the ICU to specialized inpatient units, to general pediatrics).

In designing the materials for the toolkit, the Working Group focused on the types of materials that would be useful for hospital-based health care providers, including physicians, nurses, and emergency care providers. Although the materials may also be of use to mental health professionals who work in healthcare settings this is not the principle audience for the toolkit. The toolkit uses different formats and types of materials, which together and individually are meant to provide: an introduction to traumatic stress as it relates to children facing illness, injury, and other medical events; practical tips and tools for health care providers; and handouts that can be given to parents that present evidence-based tips for helping their child cope.

All of the materials are available on the NCTSN Web site for downloading as portable document format (PDF) files, with brightly colored drawings of children and families. These materials are designed for work with any child who is developmentally able to understand and articulate things like "what worries them the most" or can make associations between reminders and feeling upset at reminders. Most of the materials are geared toward school-aged children, with some specialized material for adolescents. The specific ethnicity and gender of the child is left rather vague in most materials to allow maximum amount of identification with the material for families from different parts of the country and different cultures of origin. Each part is discussed briefly below, with some examples.

FOR HEALTH CARE PROFESSIONALS

Medical Traumatic Stress: What Health Care Providers Need to Know (Brochure)

The "Medical Traumatic Stress: What Health

Care Providers Need to Know" is a simple, three-fold brochure which briefly outlines the symptoms of traumatic stress, ways to assess and prevent distress, provide emotional support, and help the family. A few basic facts are provided about what causes development of traumatic stress symptoms, and why they are a problem for some children and parents. It is attractively presented, easy to read, and fits in a pocket.

D-E-F Protocol for Assessing and Treating Traumatic Stress in Ill and Injured Children (Pocket Cards)

They are as follows:

- A. Traumatic Stress in Ill or Injured Children: After the ABCs Consider the D-E-Fs
- B. How to Assess and Help: Distress
- C. How to Assess and Help: Emotional Support
- D. How to Assess and Help: Family

Each of the pocket cards is a colorful and easy reference to the basic principles of working with children in the hospital for serious illness or injury. They are attached together and designed to fit in the pocket of a white coat. The PDF version of the pocket cards can also be downloaded into a personal digital assistant (PDA) or handheld device. Each card includes a outline of how to assess, and how to help, in a specific domain. For an example see the Quick Screen [Table 1]).²²

Pediatric Medical Traumatic Stress: A Comprehensive Guide

This educational document in the Toolkit provides an overview of the other materials available, and how to get them, the symptoms of traumatic stress, and a prevention model. The 12-page guide reviews all of the material on the D-E-F cards, tools that are available for assessment of children and families, and suggested reading.

Pediatric Medical Traumatic Stress Toolkit: Your Guide to Using the Toolkit Effectively

The stories of two children—Tommy, a school-aged boy struck by a car, and Maria, an adolescent girl newly diagnosed with cancer—are used to illustrate ways in which the toolkit materials could be useful to providers at different points in the continuum of care. Examples of how to use the D-E-F model are provided for Admission, Diagnosis and Treatment Planning, Adjustment to Inpatient Treatment, Coping with Painful Treatment, Treatment Setbacks,

Discharge Planning, and Outpatient Treatment for Maria, and for PreHospital, Emergency, Inpatient, Rehabilitation, Discharge Planning, and Outpatient care for Tommy.

FOR PARENTS

Medical Traumatic Stress: Suggested Resources for Parents (Handout)

This single sheet includes selected books and articles, as well as selected Internet sites that would be appropriate for parents. This can and should be updated periodically.

Tip Sheets

- A. At the Hospital Helping my Child Cope—What parents can do.
- B. After the Hospital Helping my Child Cope—What parents can do.
- C. At the Hospital helping my Teen Cope—What parents can do.

These three sheets, each two sides of a page

TABLE 1.

Quick Screen: Is this child at risk for ongoing traumatic stress reactions?

ASK PARENT

Since this has happened, does your child...

- ☐ Get Physical symptoms if reminded of the illness or injury?
- ☐ Try not to Talk about it?
- ☐ Startle easily (for example, jump at sudden noises)?
- ☐ Get very Distressed if reminded of the illness or injury?

ASK CHILD

- ☐ Have you been really scared or thought you might die?
- ☐ Does a sudden noise really make you jump?
- ☐ Do you feel very upset when something reminds you of being sick or hurt?
- ☐ Do you have people who care about you and pay attention to what you say?

REMEMBER RISK FACTORS

- ☐ Severe pain at any time?
- ☐ Exposed to scary sights and sounds?
- ☐ Separated from parents or caretakers?
- ☐ Loved ones ill or injured? Did anyone die?
- ☐ Other losses such as home, pet, belongings?
- ☐ Is child mourning loss of ability, body image, or future?
- ☐ Prior scary experiences?
- ☐ Prior behavior problems?

If multiple concerns or risk factors present, arrange follow-up and consider referral for further assessment.

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long, describe the typical symptoms of traumatic stress, the types of incidents which can lead to traumatic stress symptoms, and specific, age-appropriate suggestions about what to do to help.

Typical Excerpts from the "Tips for Parents"

- You are the best person to help your child. Although it may be difficult, try to be calm and reassuring. Give frequent hugs and praise. Hold your child's hand during tests and procedures, and distract your child with stories and pictures.
- Be patient with your child but don't be afraid to set normal limits. Children's reactions can include crying, temper tantrums, whining, clinging and acting out in frustration. These feelings and behaviors are common but temporary. Remind your child that it's okay to be scared or cry.
- Help your child understand what is happening. Use simple terms that he or she can understand. If your child needs to go through a painful procedure, be honest about the fact that it may hurt but also explain its purpose is to help him or her feel better.
- Allow your child to talk about worries or feelings about being in the hospital. Younger children are often better at "talking" through play, drawing pictures and story-telling. Watch and listen to your child, and help them understand that their feelings are normal.
- Talk about your feelings together. Children often know more than they admit, but they can easily misinterpret information or other people's feelings. Ask questions to figure

TABLE 2.

**How to Assess: Distress
Traumatic Stress in Ill or Injured Children**

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

- Current pain: "How is your pain right now?"
- Worst pain: "What was the worst pain you have had since this happened?"

Fears and Worries:

- "Sometimes children are scared or upset when something like this happens. Is there anything that has been scary or upsetting for you?"
- "What worries you most?"

Grief or Loss:

- Anyone else hurt or ill?
- Other recent losses? (loss/damage to home, pet, etc.)

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out what they know and what they imagine. Reassure your child that he or she has not done anything wrong.

- Help your child see the hospital staff as helpers. Remind your child that the staff has a lot of experience helping sick and injured children feel better. Encourage your child to participate by asking his or her own questions to the doctors or nurses. It's important for you to have accurate information, so ask your own questions too.
- Young children are often more affected by being left alone. Have a family member or familiar adult stay with your child as much as possible. Always tell your child when you are leaving, why, and when you will be back.
- Take care of yourself. If you are worried, upset, or not getting sleep, it will be harder to help your child. Don't be afraid to ask friends

or family for help. Talk about your worries with other adults, such as family, friends, clergy, a counselor or your doctor.

USING THE TOOLKIT

Several thousand copies of the Toolkit have been disseminated to children's hospitals across the US over the past year. Many additional copies have been downloaded from the NCTSN Web site. It seems that nursing staffs have been the primary consumers in hospitals to this point. Toolkits have been used successfully in grand rounds presentations in pediatrics to reach the physicians; in service training to reach nurses, social workers, and emergency personnel; and noon conferences to reach residents and fellows.

Surveys distributed with copies of the Toolkit have yielded reports that the materials in the Toolkit have been found to be useful and informative. Most healthcare professionals who have tried them have indicated that they will use them in practice in the future.

ADAPTATION OF THE TOOLKIT

The concept of providing basic guidelines for professionals and handouts for parents has applicability for other areas where traumatized children are found. This framework is now being adapted for use with child welfare workers and foster care families. The format and content is also being examined for applicability to disaster and terrorism situations. An extension of the principles will be applied to work within primary care settings.

CONCLUSION

Children dealing with serious illness or injury are at risk for the development of acute and chronic symptoms of traumatic stress. The healthcare providers in the hospital are in a position to prevent further traumatic events, recognize traumatic stress symptoms, and help parents to intervene. Practical and attractive guidelines and information to healthcare providers in the acute setting, and handouts for parents to take home with them, can provide a simple but effective way to help children and their families to fully recover from injury and illness. These are now available as a free downloadable PDF files from the National Child Traumatic Stress Network Web site, at NCTSN.net.org. **CNS**

TABLE 3.

How to Help: Distress

Tips to Help Families of Injured or Ill Children

Provide the child with as much control as possible over the clinical encounter. The child should:

- Understand what is about to happen
- Have a say in what is about to happen
- Have some control over pain management

Actively assess and treat pain

- Use your hospital's pain management protocol

Listen carefully to hear how the child understands what is happening

- After explaining diagnosis or procedure, ask the child to say it back to you
- Remember that the child's understanding may be incomplete or in error
- Ask the child to say it back to you

Clarify any misconceptions

- Provide accurate information.
- Use words and ideas the child can understand

Provide reassurance and realistic hope

- Describe what is being done to help the child get better.
- State that there are many people working together to help the child

Pay attention to grief and loss

- Mobilize your hospital's bereavement service and/or grief protocols
- Encourage parents to listen to their child's concerns and be open to talking about their child's experience

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