Working with Children and Families Experiencing Medical Traumatic Stress:

A Resource Guide for Psychosocial Professionals
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PURPOSE OF THIS RESOURCE GUIDE:

This resource guide is designed to help psychosocial professionals who are working with children and families impacted by illness or injury. It is also intended for psychosocial providers who receive referrals from healthcare providers and healthcare teams. These psychosocial professionals include clinical social workers, mental health counselors, psychologists, psychiatrists, and others. This guide provides: an overview of pediatric medical traumatic stress (PMTS) based on the most recent research; resources and materials to educate medical colleagues (physicians, nurses, physician assistants); and psychosocial screening, assessment, and intervention resources and materials.

We recognize that there are many ongoing stressors that children and families endure after diagnosis of an illness or an injury. The purpose of this guide is to focus specifically on medical traumatic stress and responses that children and families may have.

This guide aims to:
- Increase knowledge of pediatric medical traumatic stress
- Define pediatric trauma-informed care
- Support the implementation of trauma-informed pediatric care
- Support psychosocial providers in collaborating with medical providers about PMTS
- Provide psychosocial professionals with tools to screen, assess, and prevent PMTS, as well as administer interventions to treat PMTS

OVERVIEW: PEDIATRIC MEDICAL TRAUMATIC STRESS

In the United States, illness and injury are common among children and adolescents. Each year:
- Approximately 20 million children are injured, resulting in 8 million emergency room visits
- Over 11,000 children are diagnosed with cancer
- More than 1,000 children undergo organ transplant
- Approximately 5% of children and adolescents are hospitalized for acute or chronic illness or injury
- Approximately 30% of children newly diagnosed with Type 1 diabetes require hospitalization and intensive care treatment
- Nearly 1 million children and adolescents make emergency room visits for a life-threatening asthma episode
- Between 15,000 and 30,000 children under 15 are hospitalized for burn injuries

Pediatric injury, ambulance transportation, diagnosis of a chronic or acute illness, medical treatment, medical procedures, and hospitalizations may be traumatic for children and their families. However, not all children and families describe contact with the healthcare systems as traumatic. Medical events may be more likely to be experienced as traumatic when they involve:
- Sudden or unexpected onset of the illness or injury
- Painful or frightening treatment procedures
- Sights, sounds, or experiences in the hospital that are upsetting or frightening
- Perceived threat of death or serious harm to self or others (despite whether this risk was objectively present)

Pediatric medical traumatic stress involves exposure to a potentially traumatic medical event and subsequent traumatic stress reactions, such as re-experiencing, avoidance, and hyper-arousal as well as changes in mood, cognitions and behavior. These reactions may persist over time and interfere with recovery from injury or illness and/or with return to normal activities. In addition to the child with illness or injury, parents, siblings, extended family members, and other loved ones are at risk for medical traumatic stress.

While many families adapt and cope with the stress related to pediatric injury and illness, all children and families would benefit from medical care that is sensitive to the potentially traumatic nature of medical conditions and treatments and a substantial subset of children and families would benefit from psychosocial support and intervention.
POTENTIALLY TRAUMATIC MEDICAL EVENTS

Traumatic medical experiences are rarely a single event. All along the continuum of healthcare, ill or injured children and families face multiple traumatic experiences, as well as incidents that will trigger feelings or remind them of those experiences. In addition, traumatic stress doesn’t necessarily end with the conclusion of medical treatment.

Factors that contribute to experiencing medical events as traumatic:
• A specific scary or shocking event (injury / initial diagnosis)
• The medical environment (hospital sights / sounds, etc.)
• Pain or painful medical treatment
• Separation from caregivers or family members
• Physical limitations or impairment
• Ongoing uncertainty about prognosis
• Treatment setbacks
• Caregiver helplessness seeing their child in pain, distressed, hooked up to medical equipment, etc.
• Exposure to distress, pain, or death of others (e.g., other patients)
• Exposure to reminders of past traumatic medical experiences
• Sense of life threat (regardless of objective prognosis)

Children, teens, and their adult caregivers can differ significantly in what they perceive as traumatic in the hospital or other medical setting. For children, concrete, immediate consequences – getting needles and painful procedures, scarring and physical changes or disabilities, and pain often lead to distress. For teens, immediate physical consequences, as well as the social consequences of being in the hospital - being isolated from friends and family, missing school, etc. can be the important predictors of distress. For caregivers, thoughts and feelings around the diagnosis and prognosis may be described as traumatic.

TAKE-HOME MESSAGE FROM THE RESEARCH DATA:

What counts in risk for traumatic stress is NOT the objective severity of the child’s illness or injury, but the SUBJECTIVE experience of the child or parent.
I.e. Are they feeling scared or helpless? Do they think they might die?

WHAT IS THE MOST TRAUMATIC?

Kids and parents see things differently.

<table>
<thead>
<tr>
<th>Child cancer survivor:</th>
<th>Moms of cancer survivors:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Shots</td>
<td>1. Worried about relapse</td>
</tr>
<tr>
<td>2. Losing hair</td>
<td>2. Pain</td>
</tr>
<tr>
<td>4. Pain</td>
<td>4. Diagnosis – Finding out</td>
</tr>
<tr>
<td>5. Bone marrow procedures</td>
<td>5. Know that others died</td>
</tr>
<tr>
<td>6. Know others that died</td>
<td>6. Feeling sad/scared</td>
</tr>
<tr>
<td>7. Scared about death</td>
<td>7. Staying in hospital</td>
</tr>
<tr>
<td>8. Worried about relapse</td>
<td>8. Shots</td>
</tr>
<tr>
<td>10. Diagnosis - Finding out</td>
<td>10. Losing hair</td>
</tr>
</tbody>
</table>

Research with ill and injured children and families has shown that children and caregivers may find different aspects of the experience traumatic.
PEDiatric Medical Traumatic Stress reactions

As with other types of trauma, emotional and behavioral reactions to potentially traumatic medical events include:

- General anxiety symptoms
- Worry about safety
- Hypervigilance
- Agitation
- Temper tantrums
- Feeling sad or withdrawn
- Problems with sleep; nightmares
- Problems with eating
- Trouble focusing or concentrating
- Feeling numb or seemingly detached
- Behavioral regression (bedwetting, separation anxiety, etc.)
- Difficulty in school / absenteeism
- Avoidance of triggers (e.g., medications, eye contact with doctors, delaying appointments)

In addition, children and adolescents may have strong emotional reactions to medical reminders, such as: getting upset at going to the doctor for routine check-ups, adverse reactions to pills and needles, reactions to seeing or passing by hospitals and ambulances, etc. Being sick or immune-compromised can lead to serious health problems, thus children may have realistic concerns with exposure to illness. Children who have experienced a potentially traumatic medical event may begin to generalize their experience, possibly manifesting itself in a preoccupation with their own health or the health of others, may avoid others with common illnesses, and may have obsessive thoughts and actions around cleanliness and germs.

Somatic complaints, which are often associated with traumatic stress reactions, need to be approached more carefully. Children and adolescents who have experienced illness and injury may experience stomachaches, headaches, and nausea, as well as other sensory reactivity. Teasing apart the extent to which these complaints have an identifiable medical cause is important. Whatever their cause, somatic complaints may be interpreted in a more catastrophic manner by children who have experienced medical traumatic stress.
UNIQUE FEATURES OF PEDIATRIC MEDICAL TRAUMATIC STRESS

Many psychosocial professionals are familiar with child trauma and traumatic stress related to child abuse, neglect, and exposure to violence. Medical trauma has some distinct characteristics that may impact the course of traumatic stress symptoms and have implications for medical care and psychosocial intervention, including:

• **Experience of pain / ongoing pain:** Illness and injury often involve acute pain, and may involve chronic pain. Healthcare systems are paying increasing amounts of attention to pain (as the “fifth vital sign”) and to optimizing pain management. Nonetheless, during and after medical treatment, children may experience pain that is not well controlled. Children often have little experience with managing pain and may make catastrophic interpretations regarding the meaning of the pain. Children with pain can readily become emotionally and behaviorally dysregulated and frequently do not know how to manage their pain without outside intervention.

• **Painful / distressing procedures:** Children with a serious illness or injury may have to undergo multiple painful or distressing procedures, which can be frightening for them. Anesthesia and other medications often help lessen procedural pain. Healthcare teams and parents can provide effective distraction to lessen distress during procedures. But often, the child or teen has to endure some pain during or after procedures.

• **When a child has repeated procedures over time, she or he may develop anticipatory anxiety,** which can result in behavioral dysregulation or treatment refusal, and can impact overall medical treatment adherence.

• **Sedation and loss of consciousness:** Loss of consciousness – whether due to a traumatic injury or to sedation / anesthesia - can be disorienting or scary to both children and their caregivers. Not being able to place events in time and sequence can maintain traumatic stress symptoms. Children sedated while in intensive or critical care, or who are coming out of anesthesia, may also experience frightening hallucinations that they believe to be real. These experiences have been linked to increased traumatic stress reactions. In rare instances, children and teens recount hearing people saying things about them while under sedation. In addition, a few children have recalled coming to consciousness during surgery while feeling traumatized at being physically paralyzed by the sedation and unable to talk or communicate.

• **Separation and isolation:** When injury or illness have a sudden onset, children and teens may initially be separated from caregivers during ambulance transport or emergency treatment, which can be very frightening and cause significant distress. Most parents and caregivers try to maximize time with their hospitalized child. But caregivers often need to work or attend to other children, and children in the hospital often spend considerable time without a parent present. Lengthy hospital stays also mean that children are separated from family, friends, and pets, and can feel isolated from their usual support system.

• **Exposure to sickness, injuries, or death of others:** While hospital personnel and systems do their best to shelter children and families from unnecessary exposure to other frightening events, sometimes these are unavoidable. Children in the emergency room or inpatient hospital may see other seriously injured or ill patients and their families, see and hear frightening sights and sounds (e.g. resuscitations, alarms), and may experience grief and loss when other patients die. Injured children and teens may be exposed to traumatic elements at the scene of an accident, shooting, or other traumatic event before being brought to the hospital. They may have seen bloodied or broken body parts, witnessed emergency procedures like CPR being performed on others, or noticed faces of those who are upset, scared, or crying. These images can be etched in their memories long after the injuries have healed.

• **Ongoing physical and health consequences:** For some children and families, the potentially traumatic medical events do not have a clear end point. The ongoing possibility of recurrence or life threat is a realistic concern in many conditions. Chronic illnesses, like diabetes, asthma, or sickle cell disease can have life-threatening episodes and consequences and require ongoing management and vigilance. The course of some cancer treatments may take years to complete and may involve both life-threatening complications and relapse. Some injuries bring permanent scars and physical alterations, disabilities, and loss of prior functioning. For many children and families, ongoing physical consequences and treatment can serve as reminders of trauma and loss. Other families may live under heightened threat and hypervigilance, fearing a treatment complication or relapse. Still others might try to avoid these feelings by avoiding needed medical treatment, unfortunately increasing their risk for medical complications.
**FAMILY IMPACT:**

Medical events do not just impact children; they impact the entire family system. When medical events create a crisis, families often naturally reorganize roles and tasks in order to support the ill or injured child and cope with the impact of the trauma. Family attention, goals, and priorities can suddenly and dramatically shift. Many families will make adjustments, balance medical and non-medical family priorities, and return to their prior level of functioning after the immediate medical crisis is over.

Some families, however, have a difficult time re-stabilizing due to ongoing worries, concerns, or consequences from the medical event. Even when the crisis is over and the child has returned to prior functioning, some caregivers remain on guard and hypervigilant and often describe themselves as “waiting for the other shoe to drop.”

Siblings, in particular, can suffer during this time of medical crisis. When family priorities shift, siblings often feel they have been relegated to the lowest priority. They may have to parent themselves, or be parented by friends or extended family members. This loss of parental attention can be very distressing for them, which they sometimes translate as being unloved. They may also have very conflicting feelings – feeling worried and sympathetic for their ill or injured sibling, yet also feeling very jealous.

Caregiving roles also change during a medical event. Many caregivers feel unprepared and unskilled at caring for or even parenting their ill and injured child, relying a great deal on the medical team for help, support, and guidance. Parents can feel both helpless and guilty at not being able to adequately care for their child. They may also tend to relax the disciplinary rules for the ill or injured child, due to feelings of sadness or guilt. Some caregivers also feel guilty about not being able to be in multiple places at once and often have to choose between competing priorities. They also may have to make decisions under duress, and feel uncertain regarding whether they were making the right decision. Later in this guide we describe the use of the Pediatric Psychosocial Preventive Health Model (PPPHM; see image on page 23).
PREVALENCE OF PEDIATRIC MEDICAL TRAUMATIC STRESS

The chart below shows the estimated prevalence of reported posttraumatic stress symptoms in children and their caregivers. A caveat: There is variation across studies, and some injury or illness groups have received more research attention than others.

WHO IS AT HIGHER RISK FOR MEDICAL TRAUMA?

Research has identified a number of factors that are associated with higher risk for pediatric medical traumatic stress among children and caregivers.

<table>
<thead>
<tr>
<th>Factor</th>
<th>Children / Patients</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived risk of life threat</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Experienced early traumatic stress symptoms</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Experienced more severe levels of pain</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Exposed to scary sights and sounds in the hospital</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Separated from parents or caregivers during / after trauma</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>History of previous traumatic experiences</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>History of behavioral, emotional, or other mental health problems</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Lack peer support</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Have experienced other life stressors or disruptions</td>
<td>✓</td>
<td></td>
</tr>
</tbody>
</table>
DEVELOPMENTAL IMPACT OF MEDICAL TRAUMATIC STRESS:

The way that children respond to potentially traumatic medical events is influenced by their age and development.

Younger children’s responses are often behavioral and somatic; they will SHOW you that they are upset, rather than tell you.

**YOUNGER CHILDREN:**
- Do not recognize or anticipate danger until it happens.
- Can experience separation from caregivers, siblings, and/or pets as traumatic.
- Do not have the cognitive and regulatory capacity to calm their own fears, and so they may have strong startle responses, night terrors, or aggressive outbursts as a result.
- Depend on caregiver presence and support to soothe and calm them more than any other age group.
- Think in images and are more likely to process trauma through play, drawing, and storytelling, rather than talking.
- Can regress behaviorally (bed-wetting, thumb-sucking, etc.) in response to distress.
- May not understand that some losses and/or illnesses are permanent.
- Need routine, predictability, and behavioral limits to reestablish feelings of safety and security.

School-age children will take cues from adults’ non-verbal behaviors regarding how serious the illness or injury is, and how to respond.

**SCHOOL-AGE CHILDREN:**
- May discount verbal explanations if what they observe does not match up with what adults are telling them.
- Can overestimate life-threat or severity of condition based on sights, sounds, or past experiences.
- Will use their imagination to “fill in the blanks” (e.g. magical thinking) in the absence of realistic information or explanations (especially about diagnosis, prognosis, etc.)
- Sometimes imagine that an illness or injury is punishment for something they did wrong.
- Often react out of frustration and helplessness; as a result, responses can be impulsive, but are not necessarily intentional.
- Can experience significant grief and loss reactions, even if the loss was expected.
- Need routine, predictability, and behavioral limits to reestablish feelings of safety and security.

Adolescents can be more concerned about the “here and now” issues rather than the future.

**ADOLESCENTS:**
- Can be unrealistic in their expectations or beliefs about prognosis, recovery, etc.
- Will sometimes act “grown up” and try to protect others from their more distressing thoughts and feelings.
- Are sensitive to being excluded from discussions of their condition, treatment, etc.
- Are self-conscious about looking different or being isolated from peers.
- Can experience significant pain, anger, or frustration when challenged to do something that was once routine.
- Responses can include withdrawing or acting out (intense anger, emotional outbursts, increased aggression, etc.) in response to stressors and feeling dependent on others.
- Need age-appropriate opportunities for choice and control; as well as plenty of emotional support from friends and family.

**ROLE OF BELIEFS:**

Beliefs play an important role in the immediate response of children and families to a potentially traumatic medical event, as some beliefs may interfere with medical care and long-term coping.

Take for example, a 4 year old girl with no family history of cancer, who is suddenly diagnosed with leukemia and has to undergo three years of chemotherapy. Or, an 8 year old boy who is gravely injured when the limb of the tree holding his swing suddenly breaks and falls on top of him. It is human nature to seek explanations and understanding for why traumatic events occur, especially when they seem out of the blue and without justification. Pediatric illnesses and injuries are no different. Many caregivers struggle with explanations when their child suddenly becomes ill or injured, and sometimes end up blaming themselves, even if, logically, they were not to blame.

Children will “fill in the blanks” with their own explanations, and, like adults, sometimes they will blame themselves or view the illness or injury as punishment for something they did wrong before the illness or injury occurred.

Having no explanations or no one to blame can increase a child’s or caregiver’s sense of helplessness, which can also amplify traumatic stress responses. Asking children and caregivers about their beliefs about the cause of the illness or injury is important, as this information can help to identify the level of psychosocial needs and type of intervention needed (e.g., psychoeducation, more formal evidence-based preventive intervention). For example, some children and families would benefit from basic education about medical treatment and typical emotional reactions to pediatric injury and illness. By “filling in the blanks” in a developmentally appropriate manner, unhelpful beliefs about self-blame and punishment may also be dispelled. The families’ focus may then shift to more adaptive beliefs about their coping strengths and abilities.
TRAUMA-INFORMED CARE

TRAUMA-INFORMED CARE AND FAMILY-CENTERED CARE

Trauma-informed care means that medical providers’ treatment of children and families minimize the potential for ongoing trauma and optimizes both emotional and physical health outcomes. Medical providers treating children should be knowledgeable about pediatric medical traumatic stress and the variability in the ways in which children and families may respond to contact with the healthcare system. Pediatric physicians, nurses, physician assistants, and other medical providers should aim to deliver family-centered care to optimize outcomes for children and families. Psychosocial professionals can collaborate with healthcare teams to promote and support patient- and family-centered and trauma-informed care.

PATIENT-CENTERED CARE:

Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions. Patient-centered care is a partnership among practitioners, patients, and their families ensuring that decisions respect patients’ wants, needs, and preferences, and that patients have the education and support they need to make decisions and participate in their own care (Institute of Medicine[IOM]; American Academy of Pediatrics [AAP]).

FAMILY-CENTERED CARE:

Incorporating aspects of patient-centered care, family-centered care is based on the understanding that the family is the child’s primary source of strength and support. Further, this approach to care recognizes that the perspectives and information provided by families, children, and young adults are important in clinical decision making (AAP).

TRAUMA-INFORMED CARE:

An organizational structure and treatment framework that involves understanding, recognizing, and responding to the effects of all types of trauma, and seeking to employ practices that do not traumatize or re-traumatize. Trauma-Informed Care also emphasizes physical, psychological and emotional safety, trustworthiness and transparency, collaboration and mutuality, and cultural sensitivity and responsiveness (National Child Traumatic Stress Network [NCTSN]; Substance Abuse and Mental Health Services Administration [SAHMSA]).

Psychosocial professionals who work directly within a healthcare setting, or who form collaborative working relationships with healthcare professionals, can help to educate medical providers about trauma-informed care. In this role, it is critical not to expect the healthcare team to take on additional tasks, but rather to support them in integrating trauma-informed and family-centered principles within existing care routines.

HOW SETTING MATTERS

WORKING TO ADDRESS PMTS IN PEDIATRIC MEDICAL SETTINGS AND OUTPATIENT MENTAL HEALTH SETTINGS

Psychosocial providers within the healthcare system or in the community each have important roles to play in supporting families coping with medical trauma.

For psychosocial providers in medical settings, it is important to consider the role trauma may play in the lives of patients and families. Consider:

• Patient and family history and prior experiences that make them vulnerable to potential re-traumatization
• How to guide medical colleagues to be more aware of traumatic experiences and provide trauma-informed care
• Collaborating with community organizations, school, and other resources to help families find a new normal

For psychosocial providers in community settings, it is important to expand one’s understanding of trauma to include medical experiences. Consider:

• Ways to collaborate with medical team
• The impact of the child’s medical condition and care and medical trauma on the entire family’s life
• When and how to seek additional resources and support in your care of a client/family
**A TRAINING MODEL: D-E-F**

In their role as (internal or external) collaborators and consultants, psychosocial professionals can offer a simple framework to support medical professionals in providing trauma-informed care to children and families. The D-E-F protocol provides a straightforward method to educate and support medical providers in specific strategies they can employ to help prevent and address traumatic stress responses in children and families. Strategies suggested by the D-E-F protocol are within the scope of practice of the physician, nurse, or other healthcare professional.

Healthcare providers are experts in treating illness, restoring functioning, and saving lives. After attending to the basics of children's physical health (the A-B-C's), providers can promote their patients' health and recovery by paying attention to the next steps — "D-E-F"

**REDUCE DISTRESS**
**PROMOTE EMOTIONAL SUPPORT**
**REMEMBER THE FAMILY**

Some simple tips to help medical providers provide trauma-informed care (i.e., D-E-F) are below. More formal training in D-E-F for healthcare professionals can be found at [www.healthcaretoolbox.org](http://www.healthcaretoolbox.org), including brief online courses that offer free nursing continuing education credits. Other D-E-F resources can also be found on the website.
CONCEPTUALIZING PSYCHOSOCIAL CARE DECISION MAKING

The Pediatric Psychosocial Preventive Health Model (PPPHM) can be used to guide assessment of psychosocial risks and inform clinical decision making (e.g., referrals for varying levels of psychosocial support). This preventive model suggests that the healthcare team provide every ill or injured child and family with basic support and information (i.e., trauma-informed care for the Universal group) and regularly screen for acute distress and risk factors to determine which children and families might need more support (i.e., Targeted or Clinical/Treatment).

Subsequent sections of this guide include key considerations when screening and assessing for distress and risk factors associated with PMTS, and intervention considerations for impacted children and families.

<table>
<thead>
<tr>
<th>RISK LEVEL (PPPHM)</th>
<th>Who are these families?</th>
<th>Professional(s) Involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>UNIVERSAL</td>
<td>Children and families are distressed, but resilient.</td>
<td>Regular healthcare team: Physicians, Nursing, Child Life, Social Work, Care Coordinators</td>
</tr>
<tr>
<td>TARGETED</td>
<td>Children and families have acute or elevated distress or other risk factors are present in the individual(s) or family.</td>
<td>Physicians, Nursing, Psychology, Social Work, Professional Mental Health Counselors</td>
</tr>
<tr>
<td>CLINICAL</td>
<td>Severe, escalating, and persistent distress is ongoing in children and families.</td>
<td>Psychology, Psychiatry, Clinical Social Work, Professional Mental Health Counselors</td>
</tr>
</tbody>
</table>

Pediatric Psychosocial Preventive Health Model

ADDRESSING TRAUMATIC STRESS IN THE PEDIATRIC HEALTHCARE SETTING

- **CLINICAL/TREATMENT**
  - Consult behavioral health specialist.
  - Intensiﬁs 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-continued support.
  - Screen for indicators of higher risk.
All family members are at risk for medical traumatic stress and level of distress is often not apparent during interactions focused on medical treatment. Regular screening for pediatric medical traumatic stress is a critical step to identifying families who would benefit from additional psychosocial support beyond trauma-informed care.

**SCREENING AND ASSESSMENT**

Screening and assessment practices facilitate triaging families to the appropriate and needed level of psychosocial care. It is important to understand the difference between screening and assessing for psychosocial risk and pediatric medical traumatic stress.

<table>
<thead>
<tr>
<th>Screening or Assessment</th>
<th>Similarities</th>
<th>Differences</th>
<th>Professional(s) involved</th>
</tr>
</thead>
</table>
| SCREENING               | • Identifies risk factors  
                          • Supports psychosocial intervention decision-making (general)  
                          • Builds rapport between professional and child/family  
                          • Supports interdisciplinary collaboration  | • Administration and scoring are brief (5 to 10 minutes)  
                          • Determines the need for more in-depth assessment  
                          • Examines broad socio-ecological family risk factors | Physicians, Nurses, Social Work, Child Life, Psychology |
| ASSESSMENT              | • Provides in-depth understanding of specified risk factor and current symptom presentation  
                          • Informs evidence-based intervention so that approach is tailored to child/family  
                          • Defines nature of problem  
                          • Provides evidence and support for diagnostic impressions | | Mental health professionals: Psychology, Psychiatry, Clinical Social Work, Professional Counselors |
SCREENING CONSIDERATIONS
Screening generally involves a brief initial determination of risk status or distress / symptoms. Screening results are used to guide next steps. Depending on the context, the purpose of screening may be to provide an initial determination of socio-ecological family risk, protective, and promotive factors, and/or to estimate individual-level risk and protective factors or traumatic stress symptoms. The PPPHM model helps guide interpretation of screening results (see below). Ideally, screening is done universally with all ill or injured children and their families. Many screening measures are designed to be administered by frontline providers, or for self-administration by children or parents.

KEY TAKEAWAYS REGARDING SCREENING:
• Screening is intended to be brief and support triage of limited psychosocial resources
• The screening tool selected might should have been evaluated with the relevant patient population and found to be feasible for the setting
• Psychosocial providers in medical settings may be administering screens AND/OR receiving referrals due to screening
• Screening can be an opportunity for collaboration with medical providers
• As screening requirements are implemented in medical settings, it is important for administrators, medical providers, and psychosocial providers to work together on workflow
• Universal screening has potential to mitigate disparities in care

For more information on screening tools, please visit: www.healthcaretoolbox.org/find-screening-and-assessment-tools

<table>
<thead>
<tr>
<th>RISK LEVEL (PPPHM)</th>
<th>Screening Risk Level</th>
<th>Next Steps dependent upon Risk Level</th>
<th>Professional(s) involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLINICAL</td>
<td>HIGH</td>
<td>Refer for further Assessment and Evaluation</td>
<td>Mental health professionals: Psychology, Psychiatry, Clinical Social Work, Professional Counselors</td>
</tr>
<tr>
<td>TARGETED</td>
<td>MODERATE</td>
<td>Dependent upon specific child / family needs or risk factors: Refer for further Assessment and Evaluation OR Provide interventions specific to symptoms and adherence needs AND Monitor ongoing distress</td>
<td>Physicians, Nursing, Psychology, Social Work, Professional Counselors</td>
</tr>
<tr>
<td>UNIVERSAL</td>
<td>LOW</td>
<td>Psychology, Psychiatry, Clinical Social Work, Professional Mental Health Counselors</td>
<td>Regular healthcare team: Physicians, Nursing, Child Life, Social Work, Care Coordinators</td>
</tr>
</tbody>
</table>
ASSESSMENT CONSIDERATIONS

Elevated levels of psychosocial risk may indicate the need for a more in-depth, domain specific assessment to be conducted by psychology, psychiatry, or other another clinical mental health provider. There are specific considerations to be aware of when working with ill or injured children and families. It is important to find ways to meet with each family member individually, as this format allows space for more open emotional reactions to the medical and other potentially traumatic experiences. Some caregivers and children may be hesitant to separate from each other, particularly soon after the medical event. Being flexible and creative in ways to obtain privacy while considering the family members’ preferences are key.

ASSESSMENT DOMAINS

An assessment for pediatric medical traumatic stress can be conducted in much the same way that you would assess for posttraumatic stress symptoms related to other types of potentially traumatic events. Ideally, all family members at elevated risk should be assessed. A multi-domain assessment may include:

- behavioral, emotional, and social functioning
- social/attachment history
- physiological arousal
- cognitive and academic functioning
- beliefs
- trauma symptoms and impact on daily functioning
- trauma history and exposure

STANDARDIZED QUESTIONNAIRES

Standardized questionnaires should be used to assess symptoms and/or functioning across the above mentioned domains. Assessment for pediatric medical traumatic stress may include a range of mental health symptoms, that frequently co-occur and can impact health outcomes. For example:

- Trauma or stress-related difficulties (e.g., Acute Stress Disorder / Posttraumatic Stress Disorder)
- Anxiety (e.g., Generalized Anxiety Disorder, Obsessive Compulsive Disorder)
- Mood difficulties (e.g., Major Depressive Disorder)
- Behavioral problems (e.g., Oppositional Defiant Disorder, Attention Deficit Hyperactivity Disorder)
- Substance use problems

Visit link below for information on assessment instruments:
www.healthcaretoolbox.org/tools-and-resources/tools-you-can-use-assessment.html

CLINICAL INTERVIEW CONSIDERATIONS

It is important to gather information about current emotional reactions, perceptions of the medical event, treatment, hospitalization, and prognosis, and about current and past coping strategies and other relevant psychosocial history. Clinical interviews in this context often do not lead to a formal psychological assessment report, but rather to practical guidance for the healthcare team and psychosocial professionals.

Understanding the child’s and family’s experiences with regard to the following elements should be prioritized in psychosocial history-taking for children facing illness, injury and other medical events:

ASPECTS OF CURRENT/MOST RECENT MEDICAL EVENT(S):

- Was alone / without caregiver for initial or lengthy parts of treatment
- Illness / injury was sudden and scary
- Treatment is painful or scary
- Was unprepared for / did not understand treatment
- Experienced scary sights and sounds in hospital / during treatment
- Felt isolated from friends and family during hospital / treatment
- Missed school for lengthy periods of time due to injury / illness
- Has strong emotional or fear reactions towards going to doctor / dentist, getting shots, seeing ambulances, and being in or near hospitals
- Overreacts to minor injuries / illnesses
- Is hypervigilant regarding illness or injury in self / others
- Is preoccupied with one’s health or avoiding germs, contamination
- Has had to change or see different medical providers frequently

HEALTH HISTORY:

- Chronic or serious illnesses
- Serious injuries (accidents, dog bites, violence)
- Life-threatening allergies / allergic reactions
- Current medication use for health conditions
- Current pain level
- Scars, handicaps, or physical disabilities
- History of substance use (particularly in adolescents)
- Family psychiatric history
PRIOR POTENTIALLY TRAUMATIC MEDICAL EVENTS, INCLUDING:

- Surgeries
- Emergency room visits
- Ambulance transports
- Lengthy hospital stays
- Unexpected hospital stays
- Prolonged or painful treatments (blood transfusions, surgical pinning / casting, spinal taps, invasive procedures)
- Knows someone else in family with serious illness, injury, or prolonged hospitalization
- Knew other sick or injured children in the hospital / knew someone who died
- Family member was also injured or ill as a result of the trauma

*And any other potentially traumatic events, such as a history of child abuse, exposure to domestic violence, traumatic grief, etc.

The goal of the assessment process is to provide both the healthcare team and the psychosocial professionals involved with a clearer picture of the needs and strengths of children and families at the Targeted and Clinical* levels. Most importantly, the assessment process supports professionals in selecting and facilitating appropriate evidence-based interventions with ill or injured children and their families. The next section will discuss special intervention considerations for the ill or injured child and their family.

INTERVENTION CONSIDERATIONS

Interventions should be tailored to the individual dependent upon developmental stage and psychosocial risk level, as well as the needs and strengths of siblings and caregivers involved.

Generally, treatment for medical traumatic stress should:

- Directly address the traumatic experiences related to illness, injury, or hospitalization, and your child’s reactions to them
- Include a parent/caregiver in the treatment
- Support family needs
- Focus on reducing traumatic stress symptoms for the long run, but also on helping a child cope and function better with any current challenges
- Address any trauma symptoms in child or family members that are interfering with medical treatment

HealthCareToolbox.org and National Child Traumatic Stress Network’s website provide information on evidence-based practices you can use for trauma-exposed children and families. While specific evidence-based practices for PMTS are still in development / under evaluation, there are evidence-based practices (e.g., TF-CBT, SCCIP-ND, CFTSI) that have shown efficacy in supporting children with an injury or illness and their family in improving family-centered promotive factors and reducing symptoms (e.g., PTSS, depression, anxiety):

www.healthcaretoolbox.org/tools-and-resources/tools-you-can-use-intervention.html
http://nctsn.org/resources/topics/treatments-that-work/promising-practices#q4

Self-directed psychoeducational tools have also shown promise for helping parents support emotional recovery in injured children (AfterTheInjury website in English and in Spanish) and helping parents support child coping with ongoing medical stressors (CopingSpace.org and Cellie Coping Kits).

Mental health providers should consider the following specific elements with regard to the ill or injured child’s developmental stage, as well as to siblings and caregivers, when developing an intervention plan.

Note: The elements below apply to the index child (patient), and to siblings.

INTERVENTION CONSIDERATIONS WITH YOUNGER CHILDREN:

As noted above, younger children greatly benefit from routine, both during admissions or outpatient medical visits and at home. Younger children also will respond more readily to behavioral interventions than talk therapy. Be sure to rely on observed behavior, not just verbal report, to understand how a child is feeling and to assess for response to treatment.

<table>
<thead>
<tr>
<th>RISK LEVEL (PPPHM)</th>
<th>Screening Risk Level</th>
<th>Next Steps dependent upon Risk Level</th>
<th>Professional(s) involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLINICAL</td>
<td>MODERATE-HIGH</td>
<td>• Intensify psychosocial services</td>
<td>Mental health professionals: Psychology, Psychiatry, Clinical Social Work, Professional Counselors</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Address impact on medical treatment</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Provide trauma-specific interventions</td>
<td></td>
</tr>
<tr>
<td>TARGETED</td>
<td>LOW-MODERATE</td>
<td>• Monitor child/family distress and risk factors</td>
<td>Physicians, Nursing, Psychology, Social Work, Professional Counselors</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Provide interventions specific to symptoms and adherence needs</td>
<td></td>
</tr>
<tr>
<td>UNIVERSAL*</td>
<td>LOW</td>
<td>• Provide psycho-education and trauma-informed / family-centered support</td>
<td>Regular healthcare team: Physicians, Nursing, Child Life, Social Work, Care Coordinators</td>
</tr>
</tbody>
</table>

*Note: Typically screening will inform you (and other professionals) on next steps for low-risk families and more in-depth assessments and evaluations may not be necessary. If a child is targeted for assessment, but your assessment determines that a child/family is at Low Risk, Universal interventions are likely to meet their needs.
• Remember that parents are a main source of comfort for the child.
• Provide concrete explanations for treatment interventions and what to expect in sessions.
• Help identify and label what they may be thinking and feeling; remind them that other children often feel the same way.
• Encourage expression of thoughts and feelings through play, drawing, or storytelling.
• Tolerate regressive symptoms in a time-limited manner.
• Address distortions and magical thinking about the illness, injury, or prognosis, and help them “fill in the blanks” with realistic information.

**INTERVENTION CONSIDERATIONS WITH SCHOOL-AGE CHILDREN:**

School-age children formulate their responses based on their own perceptions and on cues provided by adults. Younger school-age children often demonstrate more concrete thinking, but the capacity for abstract thinking and self-reflection develops steadily across this age range. Ask open-ended questions to school-age children to learn what they know and, especially, what they are imagining.

- Address distortions and magical thinking about the illness, injury, or prognosis, and help them “fill in the blanks” with realistic information.
- Help them create a coherent story to tell others about what happened or will happen.
- Tell them that it is normal and expected for kids to feel afraid, angry, or sad.
- Help them acknowledge the bad things that have happened, and balance these with the good.
- Reassure the child that she or he has done nothing wrong to cause the illness, injury, or pain.
- Support activities that offer predictability, routine, and clear behavioral limits and expectations.

**INTERVENTION CONSIDERATIONS WITH ADOLESCENTS:**

Since adolescents are often concerned with “here and now” issues, be sure to address these first.

- Address their expectations regarding the illness or injury, and what could have been done to prevent or lessen the trauma.
- Help them understand that it’s common to react to extremely stressful situations by feeling angry, numb, or acting out.
- Be open to their expression of strong emotions.
- Discuss the expected strain the injury or illness might have on their relationships with family and friends, as well as potential feelings of isolation.
- Make sure they are actively involved in discussions and decisions that will impact them, and in their daily care, whenever possible.
- Help them anticipate the challenges the illness or injury will cause to their academic and social lives and problem-solve ways to overcome these challenges.
- Allow them time to acknowledge and to grieve the loss of things they can no longer do, while helping them explore and discover things they can do.
- Address distortions and magical thinking about the illness, injury, or prognosis, and help them “fill in the blanks” with realistic information.

**ADDITIONAL INTERVENTION CONSIDERATIONS WITH PARENTS / CAREGIVERS:**

- Address communication with child, partner, and others in the parent’s support system about the illness or injury and its treatment.
- Help parent communicate with the medical team.
- Help parent help child with emotional regulation and with specific traumatic stress reactions.
- Help anticipate adherence concerns with medical and psychosocial treatment.
- Provide education about developmental stages and other factors that impact the child’s (and siblings) psychosocial outcomes.
- Address caregiver’s perceptions of their own behaviors and coping strategies, their beliefs and appraisals of their child’s illness, injury, treatment, and prognosis, and the consequences of their behaviors, beliefs and perceptions for themselves and their family.
- Teach intervention skills to coincide with child interventions (ensure caregivers can support child in-home with possible emotional and behavioral concerns specific to medical traumatic stress).

**RISK LEVEL (PPPHM)**

**Who are these families?**

** Intervention needs**

**Professional(s) involved**

<table>
<thead>
<tr>
<th>RISK LEVEL (PPPHM)</th>
<th>Who are these families?</th>
<th>Intervention needs</th>
<th>Professional(s) involved</th>
</tr>
</thead>
</table>
| CLINICAL           | Severe, escalating, and persistent distress is ongoing in children and families. | - Intensify psychosocial services  
- Address impact on medical treatment  
- Provide trauma-specific interventions | Mental health professionals  
Psychology, Psychiatry, Clinical Social Work, Professional Counselors |
| TARGETED           | Children and families may have acute or elevated distress and other risk factors may be present in the individual(s) and family as a whole. | - Monitor child/family distress and risk factors  
- Provide interventions specific to symptoms and adherence needs | Physicians, Nursing, Psychology, Social Work, Professional Counselors |
| UNIVERSAL          | Children and families are distressed, but resilient. | - Trauma-informed care  
- Provide psycho-education and family-centered support  
- Screen for indicators of higher risk | Regular healthcare team: Physicians, Nursing, Child Life, Social Work, Care Coordinators |
PRACTICE CONSIDERATIONS: OUTPATIENT MENTAL HEALTH

It can be difficult for patients and families to find a mental health provider in the community that they feel understands their experiences of medical trauma. We encourage parents and families to consider many factors in searching for a clinician, counselor or mental health professional, including their discipline or specialty, appropriate professional licenses or certification, special interests and experience, populations served, and languages spoken.

UNDERSTANDING OF THE UNIQUE ASPECTS OF MEDICAL TRAUMA AND SPECIFIC CLIENT DIAGNOSES:

It can be helpful to become more familiar with:
- Specific aspects of your client/patient’s illness or injury, including typical treatment course and patient/family experiences, and
- The ways in which traumatic stress reactions can interact with ongoing health concerns and medical care.
- Client should, as much as possible, not have to explain their diagnosis to you as their therapist, and be able to focus discussion on their experiences

Where to research:
- Organizations associated with their diagnosis
- Reach out to children's hospitals with training programs
- Connect with medical team involved in the care of your client
- Identify other psychologists with expertise in this area via APA Division 54 (Pediatric Psychology)
- KidsHealth.org and other children's hospital websites

ANTICIPATORY GUIDANCE:

- Children and families, even those without ongoing health concerns, will need to interact with healthcare systems again and it is important to help them prepare for potential emotional reactions
- Support coping with new diagnoses/medical issues that may arise in the family
- Provide psychoeducation around traumatic stress responses & emotion identification
- Support around ongoing procedures and procedural anxiety
  - Evidence strongly supports the use of active distraction to reduce child distress during medical procedures. This video provide brief, focused tips for parents about serving as a “distraction coach” for children during procedures: Distraction in Action - Helping Your Child During Medical Procedures
- Medical care and procedures can cause anxiety for children and parents. Learn the signs of acute anxiety in children and techniques to minimize these reactions and increase cooperation in care through the following resources:
  - This publication from the Annals of Emergency Medicine provides helpful information as well as videos on caring for a child who may be anxious or frightened.
  - This video, currently available to New England Journal of Medicine subscribers only, provides helpful techniques to minimize procedural anxiety in children. Check your institution for access.
  - Work with families to communicate and collaborate with medical team members and prepare for medical visits
  - Facilitate connection with any non-profit organizations (potentially disease-specific) that offer support to families
  - Returning to social situations following a new diagnosis or medical event can be scary:
    - Consider with clients who would the family share this new medical issue with and who might they not share with
    - Support children in crafting explanation of a medical event or diagnosis to other children
    - Think about how children will choose to manage a new condition in public settings
    - Consider cultural variations in support networks, and remain open to including kinship networks and healing practices that the family views as helpful.

TIPS FOR COLLABORATING WITH HEALTHCARE TEAMS:

- Talk with families about collaboration with their healthcare team
  - Explore confidentiality and privacy concerns
  - Discuss pros and cons of some level of sharing with medical team
  - Obtain consent with clearly defined limits
  - Find best way to communicate directly with medical team
    - Who to contact
    - Preferred manner of communication
    - Frequency of communication
  - Consider if ever helpful to participate in medical team meetings with or without the family
  - Collaborate with psychosocial team in medical setting

WHERE TO GET MORE SUPPORT:

It can be difficult to work with families with ongoing medical concerns, especially if you feel out of your comfort zone and in need of consultation or additional knowledge related to their healthcare needs
- Reach out to children's hospitals with internship and fellowship training programs
- Potentially attend seminars on topics relevant to you
- Professional organizations relevant to the medical condition of interest
- Example: mental health provider training related to diabetes through the American Diabetes Association
- Learn through family and patient-led organizations
  - Example: Ryan’s Case for Smiles, Alongside Network; InvisiYouth Charity
- Diagnosis-specific organizations such as Dravet Syndrome Foundation and Mattie Miracle Cancer Foundation
- Join Division 54 of American Psychological Association and use listserv to identify consultants
- Conduct literature searches for best practice guidelines for the psychosocial care of specific medical populations, for example
  - Pediatric Oncology
  - Pediatric Diabetes

WHAT FAMILIES NEED—MESSAGING, ENVIRONMENT, AND ACCESSIBILITY:

When asked what they wished mental health providers knew when caring for families experiencing medical trauma, the parents and young adults who make up CPTS’s National Family Advisory Committee highlighted the importance of being mindful regarding messaging to families, as well as easing administrative and logistical concerns:

- It is important to communicate your abilities and experiences with prospective clients and families as early as your bio or practice description. Indicate your training, what evidence-based practices you use, and if you have any specialties or experience working with specific diagnoses or identities, as well as languages spoken and/or access to interpreter services.
- When possible, provide clarity and support around payment and insurance (if accepted); many families coping with medical trauma may also be dealing with the costs and stressors associated with paying for treatment or medical bills.
- Consider potential traumatization based on environment: some families may find it difficulty entering a medical building even if it is to visit a therapist office. Prior to a first session in person, consider preparing a family for what to expect upon entering your office building.
- Being sick or immune-compromised can lead to serious health problems, thus children and families may have realistic concerns with exposure to illness, or preoccupation around cleanliness and germs. Discuss expectations around masking and COVID-19 precautions.
- Telehealth: Consider accessibility of telehealth services: i.e. closed captioning, interpreters, texting services

JOIN OUR MEDICAL TRAUMA MENTAL HEALTH PROVIDER REFERRAL DIRECTORY:

CPTS maintains a directory of the names and clinical practice information of mental health professionals who choose to participate and report that they have expertise and experience working with children and families experiencing medical traumatic stress. Professionals are asked to provide information on their areas of interest and expertise. For more information or if you would like to join, visit: https://redcap.link/CPTS_Mental_Health_Provider_Directory
PROVIDER WELLNESS

Working with children and families as they cope with illness and injury, and the traumatic stress reactions that may come from those experiences, can be professionally meaningful and satisfying, leading to personal growth and “compassion satisfaction.” At the same time, providers can sometimes feel drained, upset, or frustrated, especially during times of increased workloads or heightened personal stress. Oftentimes, helping professionals may have gotten into their field due to personal experience with their area of expertise, which can make difficult cases hit close to home. Sometimes these very human responses get in the way of being optimally effective at work – contributing to tension or conflicts with patients’ families, or to stresses within the care team.

Secondary traumatic stress is “emotional distress that results when an individual hears about the trauma experiences of another” (NCTSN). Secondary traumatic stress can be acute or chronic - and eventually may affect a provider’s own emotional health and well-being.

Research suggests that the ability to identify, understand and manage one’s emotional reactions, and to integrate effective self care strategies are paramount to preventing and/or managing secondary traumatic stress. Organizations have a key role to play in prevention of secondary traumatic stress.

Individuals can consider the ABCs of self-care:

For the Provider: Working with Traumatized Children and Families

- **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**
  - Divide 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**
  - Connect regularly with family, friends, and community.
  - Use meditation, prayer, or relaxation to connect with yourself.
  - When not at work, disconnect from professional role and e-mail.

For more information on self-care and prevention and management of STS, including two online courses on the topic and hands on tools and resources, visit [www.healthcaretoolbox.org/self-care-for-provider](http://www.healthcaretoolbox.org/self-care-for-provider).

ADDITIONAL RESOURCES TO USE WITH FAMILIES

As psychosocial providers working with families experiencing PMTS, it is important to have as many tools in your toolbox as possible.

CPTS has a wide range of resources on Healthcare Toolbox, including free evidence-based tipsheets, available in English and Spanish, that can be printed and made available to families in your hospital or outpatient mental health practice. Hard copies are available for purchase

For parents and caregivers: [www.healthcaretoolbox.org/patient-education-parents](http://www.healthcaretoolbox.org/patient-education-parents)

For patients: [https://www.healthcaretoolbox.org/patient-education-children](https://www.healthcaretoolbox.org/patient-education-children)
BOOKS AND READING MATERIALS FOR PARENTS

Afraid of the Doctor: Every Parent’s Guide to Preventing and Managing Medical Trauma.

Children and Trauma: A Guide For Parents and Professionals.
Cynthia Monahan, Jossey-Bass Publishers; San Francisco; 1997

Freeing Your Child from Anxiety: Powerful, Practical Solutions to Overcome Your Child’s Fears, Worries and Phobias.
Tamar Chansky, Broadway Books; New York; 2014

Kenneth R. Ginsburg & Martha M. Jablow. Published by the American Academy of Pediatrics; 2006

BOOKS AND READING MATERIALS FOR CHILDREN AND TEENS

James J. Crist, Free Spirit Publishing; Minneapolis; 2004 (available in Spanish)

James J. Crist, Free Spirit Publishing; Minneapolis; 2004

When I Feel Scared. (for young children)
Cornelia Maude Spelman, Albert Whitman & Co.; Morton Grove; 2002

What About Me? When Brothers and Sisters Get Sick
Allan Peterkin, Magination Press; Washington D.C., 1992

See www.HealthCareToolbox.org for more resources, screening and assessment tools, interventions, and patient handouts.

SELECTED REFERENCES AND READINGS


See www.HealthCareToolbox.org for more resources, screening and assessment tools, interventions, and patient handouts.
ABOUT CPTS

The Center for Pediatric Traumatic Stress (CPTS) was founded in 2002 to address medical trauma in the lives of children and families.

The Center’s mission is to reduce pediatric medical traumatic stress through:
- promoting trauma-informed healthcare
- disseminating evidence-based practices and screening tools to pediatric healthcare providers
- training providers to recognize and address traumatic stress in children

In all that we do, we are honored and grateful to partner with patients and families and with the frontline healthcare providers who make trauma-informed care a reality every day.

If you have any questions about CPTS, please contact: CPTS@chop.edu.