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## Post Traumatic Stress in Families with Pediatric Illness

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# POST TRAUMATIC STRESS IN FAMILIES WITH PEDIATRIC ILLNESS

OLIVIA SEECOF, MD



# OUTLINE

- Behavioral Science Topic
- Introduce post traumatic stress in parents and children
- Talk specifically about post traumatic stress in families with pediatric
  - Cancer diagnoses
  - Type 1 diabetes diagnoses
  - Traffic accidents
- Discuss relationship of PTSS in parents, children and siblings
- Apply what we've learned
  - Trauma-informed care

PEDIATRIC SEXUAL TRAUMA AND  
PHYSICAL ABUSE ARE LARGE  
SUBJECTS OFTEN ASSOCIATED  
WITH POST TRAUMATIC STRESS  
THAT WILL NOT BE COVERED IN  
THIS LECTURE

# POST TRAUMATIC STRESS DISORDER (PTSD) VS POST TRAUMATIC STRESS SYMPTOMS (PTSS)

- PTSD
  - Official DSM diagnosis
  - Stressor, intrusion symptom, avoidance, negative alterations in cognitions and mood, alterations in arousal and reactivity, >1 month of time, functional significance, exclusion of other illness or substances
- PTSS
  - Not a formal diagnosis, can last any time period, a collective name given to an array of symptoms resulting from a traumatic event

## DIAGNOSTIC CRITERIA for TRAUMATIC STRESS DISORDERS

### Acute stress disorder

- a traumatic stressor
- at least 9 of 14 different symptoms – including dissociation, re-experiencing, avoidance, anxiety and arousal
- duration of symptoms: at least 3 days and up to 1 month

### Posttraumatic stress disorder

- a traumatic stressor and subjective emotional experience of fear, helplessness, or horror
- at least 1 re-experiencing symptom
- at least 1 avoidance symptom
- at least 2 symptoms that indicate negative alterations of cognition or mood
- at least 2 hyper-arousal symptoms
- significant impairment in functioning
- duration of symptoms: 1 month or more

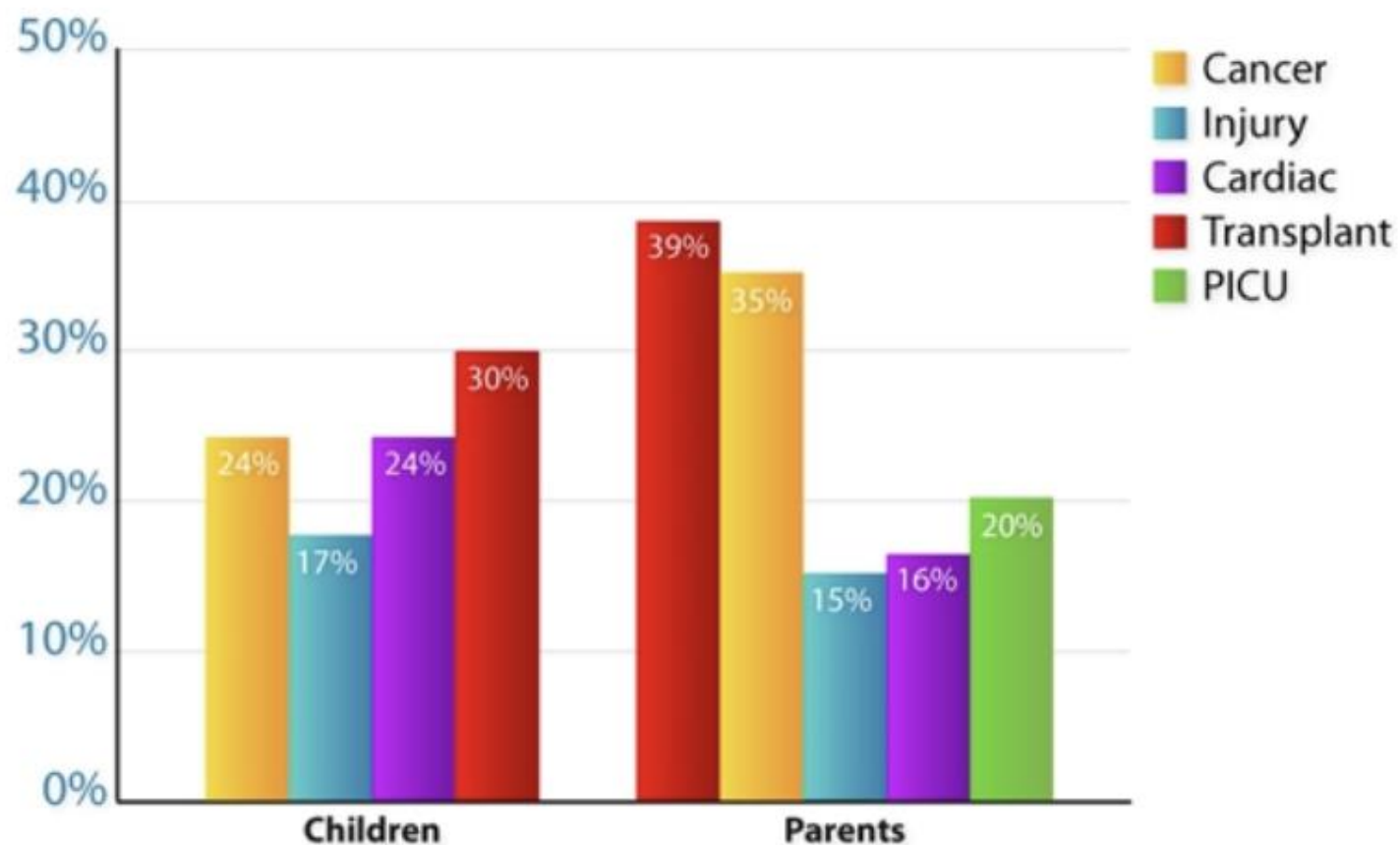
**“THREATS TO A CHILD’S HEALTH OR LIFE SUCH AS AN ACCIDENT OR THE DIAGNOSIS OF A SEVERE CHRONIC DISEASE CAN CAUSE TRAUMATIC REACTIONS IN BOTH THE CHILD AND IN HIS OR HER PARENTS.”**

# PREVALENCE

- Up to 80% of ill or injured children and their families report experiencing some traumatic stress reactions following a life-threatening illness, injury or painful medical procedure
- Between 20-30% of parents and 15-25% of children and siblings experience persistent traumatic stress reactions that impair daily functioning and affect treatment adherence and recovery



## Percent of children & parents with significant traumatic stress symptoms after medical events



Summary of research findings from The Children's Hospital of Philadelphia.  
Summarized from peer-reviewed research studies, 1999-2009.

*Note: Traumatic stress levels in children in pediatric intensive care has not yet been well-documented.*

# FACTORS THAT INFLUENCE PTSS IN PARENTS

- Illness related life-threat (severity of illness)
- Economic impact associated with the chronic illness
- Dangerous complications from treatments
- Being responsible for procedures that are painful or cause negative side effects
- Experiencing emergency hospitalizations
- Hearing about the death of young fellow patients

# HOW TO ASSESS PARENTAL PTSS

- Posttraumatic diagnostic scale
- PDS-5
  - 24 item self-report measure that assesses PTSD symptom severity in the last month according to DSM-5 criteria
  - Can yield diagnosis of PTSD
- Alt. version is the PSS-SR
  - 17 item self-report
  - Cannot yield diagnosis of PTSD

## Sample Item

Please read each statement carefully and circle the number that best describes how often that problem has been happening and how much it upset you over THE LAST MONTH. Rate each problem with respect to the traumatic event that you wrote above.

Unwanted upsetting memories about the trauma

0 = Not at all

1 = Once a week or less/a little

2 = 2 to 3 times a week/somewhat

3 = 4 to 5 times a week/very much

4 = 6 or more times a week/severe

# FACTORS THAT INFLUENCE PTSS IN CHILDREN

- Characteristics of the traumatic event and injury
- History of pre-existing anxiety or psychological difficulties or history of medical trauma
- Lacking of social, emotional and peer support
- Experience more severe levels of pain at baseline

# HOW TO ASSESS CHILD PTSS

Assess my patient for traumatic stress from a recent (within past month) injury or illness:

## Child Stress Disorders Checklist (CSDC)

**Purpose & Description:** 35 item checklist completed by parent (or nurse). Assesses acute stress or PTSD symptoms in children or teens.

**Language:** English

**References:** Saxe et al. (2003). Child Stress Disorders Checklist: A measure of ASD and PTSD in children. *Journal of the American Academy of Child & Adolescent Psychiatry*, 42(8): 972-978.

## Child Stress Disorders Checklist (CSDC) Short Form

**Purpose & Description:** 4 item subset of CSDC to be completed by parent (or physician / nurse). Assesses acute stress of PTSD symptoms in children or teens.

**Language:** English

**References:** Bosquet, Kassam-Adams, & Saxe (2010). The Child Stress Disorders Checklist-Short Form: A four-item scale of traumatic stress symptoms in children. *General Hospital Psychiatry*, 32(3): 321-327.

## Acute Stress Checklist for Children (ASC-Kids)

**Purpose & Description:** 29 item self-report checklist. Assesses acute stress reactions in children or teens.

**Language:** English, Spanish

**References:** Kassam-Adams, N. (2006). The Acute Stress Checklist for Children (ASC-Kids): Development of a child self-report measure. *Journal of Traumatic Stress*, 19: 129-139.

## Acute Stress Disorder Scale (ASDS) - (Use with children and parents)

**Purpose & Description:** 19 item self-report checklist to assess acute stress reactions in older teens.

**Language:** English

**References:** Bryant, R., Moulds, M., & Guthrie, R. (2000). Acute Stress Disorder Scale: A self-report measure of Acute Stress Disorder. *Psychological Assessment*, 12(1), 61 - 68.

Assess my patient for PTSD from a previous injury or illness

## Child PTSD Symptom Scale (CPSS)

**Purpose & Description:** 24 item self-report checklist. Assesses PTSD symptoms (and impairment) in children or teens.

**Language:** English, Spanish, Russian, Armenian, Korean

**References:** Foa, E., Johnson, K., Feeny, N., & Treadwell, K. (2001). The Child PTSD Symptom Scale: A preliminary examination of its psychometric properties. *Journal of Clinical Child Psychology*, 30(3), 376-384.

## PTSD Checklist (PCL) - (Use with teens and parents)

**Purpose & Description:** 20 item self-report checklist. Assesses PTSD symptoms in older teens and adults.

**Language:** English, Spanish

**References:** Weathers, F.W., Litz, B.T., Keane, T.M., Palmieri, P.A., Marx, B.P., & Schnurr, P.P. (2013). The PTSD Checklist for DSM-5 (PCL-5). Scale available from the National Center for PTSD at

## Child Traumatic Stress Questionnaire (CTSQ)

**Purpose & Description:** 10 item screening tool completed by child or teen. Helps identify recently injured children at higher risk for later PTSD.

**Language:** English

**References:** Kenardy, Spence, & Macleod (2006). Screening for posttraumatic stress disorder in children after accidental injury. *Pediatrics*, 118: 1002-09.

**Contact:** [j.kenardy@uq.edu.au](mailto:j.kenardy@uq.edu.au)

# GENERAL SIGNS AND SYMPTOMS OF PTSS

- Young children
  - Developmental regression like wetting the bed or sucking their thumb, increase in nightmares or temper tantrums
- School aged children
  - Use imagination to fill in what they do not understand, may feel guilt like their illness or injury is their fault
- Teenagers
  - Try to act more grown up and cover up their feelings, self-conscious or upset about being different from their peers
- Parents
  - May be overprotective, short fuse, signs of depression, feeling overwhelmed

**SOME  
SPECIFIC  
SCENARIOS**



## CASE #1

- BT is a 4-year-old boy who presents to his primary care office for a well-child visit. He is accompanied by his father and English is this family's second language. In reviewing his medical record in preparation for his visit, you see that at his 3-year-old check up, he had neck swelling that eventually led to a diagnosis of Burkitt's Lymphoma for which he has received chemotherapy and oncology follow up extensively for the last year. On exam, he is shy and not particularly interactive with office staff and providers but appears to be developing and growing appropriately. He stands by his father but will give you a high five and let you listen to his heart/lungs. His father repeatedly asks if his son can go to the dentist and when you ask about his medical history his father responds, "the cancer."



# IDENTIFYING AT-RISK FAMILIES

- Are this child and his family at risk for PTSS? Is he already exhibiting symptoms?
- As the primary care provider, should you be the one to screen this family for PTSS or is that the job of the oncologist?
- Psychosocial Assessment Tool (PAT)
  - 20 item evidence-based screening tool completed by the family unit
  - Designed for use with families of children newly diagnosed with cancer to assess psychosocial risk in these families
  - Example question: “Who can you count on to provide childcare/parenting, emotional support, financial support, information, help with everyday tasks?”

# THE DATA: PTSS IN PEDIATRIC CANCER

- In general, 30-40% of parents and siblings and 15-20% of childhood cancer survivors experience symptoms years after treatment has ended
- Differs as a function of time from diagnosis
  - More recently diagnosed patients show greater levels of symptomatology than long-term survivors
  - In parents, prevalence is 40-83% within first month post-diagnosis, dropping to 18-33% six months post diagnosis and 7-27% over 10 months post diagnosis
- Higher rates of PTSS are found among samples of older children
- Persistent symptoms in childhood cancer survivors have been associated with other psychosocial concerns in young adulthood

## CASE #2

- GR is a 6 year old male who presented to the ER after vomiting at a birthday party after eating cake and ice cream. For a few days prior to the vomiting episode, GR had been feeling a bit tired, thirsty and had wet his bed twice in the night. In the ER labs were checked that showed significant findings a blood sugar of 350, a pH of 7.3, and an anion gap of 16. He was admitted to the hospital for management of DKA and a new diagnosis of diabetes.

# THE STRESS OF T1DM

- Unique clinical scenario because both an acute and chronic illness
- Caregivers report high levels of stress related to both diagnosis of T1DM in their children as well as the burden of daily management
- The cloud of a diagnosis of a lifelong illness
- Traumatic diagnosis (hospital stay)

# THE DATA: PTSS IN T1DM

- T1DM is one of the most prevalent chronic childhood illnesses, affecting more than 200,000 youth in the US (2014 data)
- In parents of children diagnosed with diabetes, 5-24% of parents within the first 6 weeks of diagnosis experience PTSS, rising to 10-42% of parents greater than 6 months after diagnosis
  - 40% of mothers endorsed continuous emotional distress associated to their child's disease 5 years after diagnosis

# DEMOGRAPHIC RISK FACTORS?

Published in final edited form as:

*Psychol Trauma*. 2017 May ; 9(3): 325–333. doi:10.1037/tra0000230.

## **Racial/Ethnic Disparities in the Risk of Posttraumatic Stress Disorder Symptoms Among Mothers of Children Diagnosed with Cancer and Type 1 Diabetes Mellitus**

**Leilani Greening<sup>1</sup>, Laura Stoppelbein<sup>2</sup>, and Kara Cheeks<sup>3</sup>**

<sup>1</sup>University of Mississippi Medical Center, Jackson, Mississippi

<sup>2</sup>University of Alabama at Birmingham and Glenwood Autism and Behavioral Health Center, Birmingham Alabama

<sup>3</sup>Union University, Jackson, Tennessee

- Some literature has found that racial/ethnic minority groups are more vulnerable to mental health risks than majority groups
- This study
  - Did not find racial/ethnic differences in the risk of PTSS among African American vs Caucasian mothers of children with cancer or T1DM
  - Interestingly did find that mothers of children with T1DM regardless of their race/ethnicity had higher levels of cortisol compared to the mothers of children with cancer

## CASE #3

- Sisters AK (age 6) and DK (age 12) presented to their outpatient pediatric office for a follow up visit. They had been in a highway pileup car accident as restrained passengers two weeks prior to this visit. They were taken to the hospital after the accident and AK had no injuries and DK sustained a mild concussion. At this follow up visit AK is continuously talking about the accident and what happened, while DK remains sitting in the corner of the room, quiet.

# WHO WAS INVOLVED IN THE ACCIDENT?

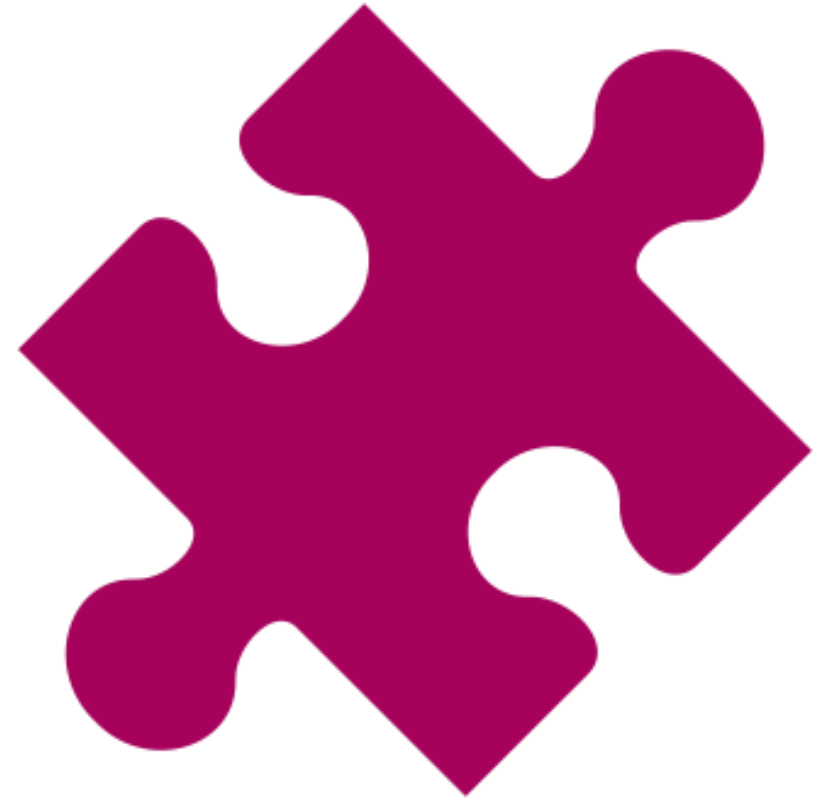
- Siblings in this case
  - How are their responses different?
- If parents are also in the accident
  - Children with accidental injuries were at higher risk of PTSD if the parents showed signs of acute distress after the incident.
  - Studies have shown that parental involvement in the accident is an important predictor of poor psychological adjustment in the child, but overall mixed evidence.



# THE DATA: PTSS IN TRAFFIC ACCIDENTS

- In western societies, road traffic accidents are among the most common traumatic events children can face
- Studies have shown 10%-35% of traffic-injured children develop PTSD or suffer from PTSS.
- Children who were passengers in MVA had higher risk of PTSS compared with pedestrians or bicycle riders (one study)
- In a study of 381 injured adolescents followed for 2 years post-injury, teens with more severe PTSS had lower health-related quality of life.

**PUTTING IT  
ALL  
TOGETHER**



# WHAT IS THE MOST DISTRESSING TO PARENTS? CHILDREN?

- In mothers and fathers, child cancer was found to have the highest rates of PTSS
- In children, accidents were associated with the highest rates of PTSS
- Why?
  - Children may not realize potential life threat of severe chronic disease, may not have been adequately informed of the seriousness of their disease. Accidents are directly experienced by child which may be frightening/distressing
- Studies of ill and injured children and their parents show that the occurrence of traumatic stress reactions is more closely related to subjective experience rather than objective medical severity

# PARENTS AND CHILDREN ARE DIFFERENT

## What is most traumatic?

Kids and parents see things differently.\*

### Child cancer survivors:

1. Shots
2. Losing hair
3. Staying in the hospital
4. Pain
5. Bone marrow procedures
6. Know others that died
7. Scared about death
8. Worried about relapse
9. Feeling sad / scared
10. Diagnosis – Finding out

### Moms of cancer survivors:

1. Worried about relapse
2. Pain
3. Scared about death
4. Diagnosis – Finding out
5. Know others that died
6. Feeling sad / scared
7. Staying in the hospital
8. Shots
9. Bone marrow procedures
10. Losing hair

\*Findings from CHOP study funded by National Cancer Institute (CA63930)

# SIBLINGS

- Research has shown some siblings feel guilt, powerlessness, loneliness, anxiety, depression and jealousy. Some exhibit poor academic achievement, difficulties in social relationships, mood disturbances and conduct problems. Others show enhanced socialization, taking on a role of helping the ill child and their parents.

## 10 Tips for Helping Siblings Cope

- 1 Be patient and give everyone time to adjust.** Members of the same family can have very different reactions and need time to adjust to the changes. Talk as a family about how the illness affects everyone.
- 2 Keep to everyday routines.** Trying to keep to some everyday routines can help things feel more normal at home. Having regular routines (e.g. meals and bed times, chores) and activities give siblings things to expect and look forward to.
- 3 Set limits as usual.** It can be tempting to relax family rules to help siblings feel special or to make up for hard times. However, it is often better to keep most of your family rules and expectations the same.
- 4 Help your other children understand what is happening.** Serious illness or injury can be confusing and scary for a sibling. Children have active imaginations and they can get the wrong idea about what is happening. Ask questions to figure out what your child knows and give information in clear, age-appropriate ways.
- 5 Encourage your other children to share their feelings.** There are many ways to share feelings (talking, drawing, story-telling, hugging) and different times (dinnertime, bedtime) and places (in the car, at home, in the hospital). Help siblings name their feelings, such as being sad, scared, angry, jealous, or guilty. Share your own feelings and be a good listener even if what they have to say is hard to hear.
- 6 Spend time with your other children.** It is important to care for your ill or injured child. But remember that your other children miss you. Try to make plans to spend one-on-one time with your other children. If you are away a lot, call regularly so you can keep in touch.
- 7 Help siblings feel involved.** Allow them to be a part of their sibling's care. Plan a visit to the hospital and introduce them to the healthcare team. Let them choose which toys and games to take to the hospital. And make sure you let them know how much you appreciate the extra things they do to help out.
- 8 Help them keep in touch.** If their ill or injured sibling is away, find ways to help your other children keep in touch. Make cards, write letters, draw pictures, make videos or arrange for video chats, record a sibling reading a bedtime story. If possible, let them visit their brother or sister in the hospital.
- 9 Encourage siblings to have fun.** Often siblings feel guilt about wanting to have fun. Remind them that it is okay for them to do the things they enjoy, like spending time with friends, or hobbies and extra-curricular activities.
- 10 Seek help.** If your other children seem to be struggling, talk to your child's doctor about seeking help from a mental health professional, such as a psychologist or social worker.

# FAMILIAL ASSOCIATIONS OF PTSS

- In 2001 Scheeringa and Zeanah introduced concept of “relational PTSD” which suggests that parent and child symptoms mutually influence each other concurrently and sustain each other over time
  - Models of maternal-child dyadic coping suggest that successful emotional adjustment of both the ill child and healthy caregiver is enhanced when each member of the dyad perceives
- PTSS found to be stable over time in children and parents, suggests there is a considerable risk of chronification of PTSS
- Cross-lagged effects from child to parent and parent to parent were not significant
  - Maternal and paternal PTSS is not influenced by child symptoms
  - Suggests that parents are more important for the course of the child’s PTSS than vice versa
- **Very mixed evidence!!!!**

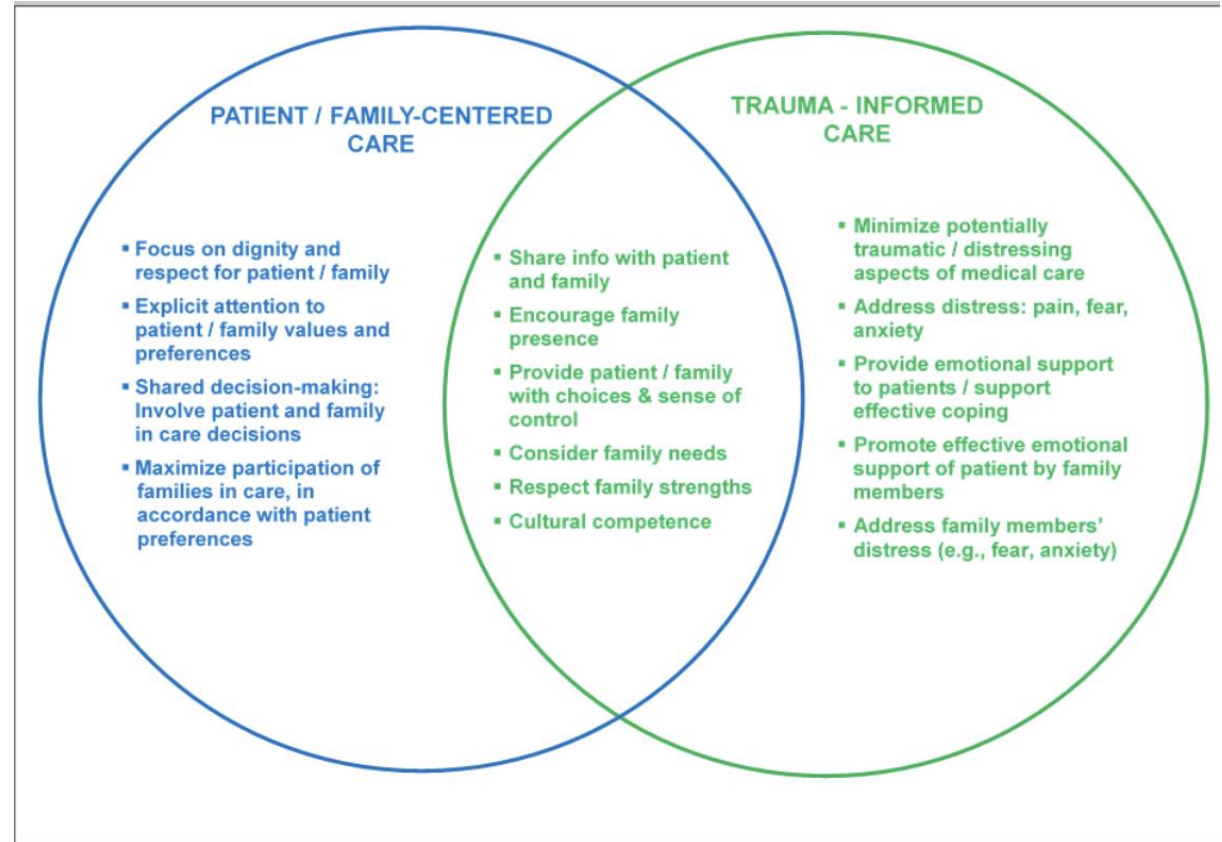
# HOW TO APPLY TO DAILY PRIMARY CARE

- Normalize the experience
  - Help patients and families understand and accept that what they are feeling is expected and not uncommon
- Provide additional support
  - Help patients and families reduce perceptions of threat, fear and helplessness while fostering a sense of control
- Explore post-traumatic growth
  - Help patients and families recognize that personal growth and stronger connections to family and friends can come from experiencing a significant pediatric illness



# BASICS OF TRAUMA-INFORMED CARE

- D: Reduce Distress, ask about fears and worries
- E: Emotional Support, who and what does the patient need now
- F: Remember the Family, gauge family stressors and resources



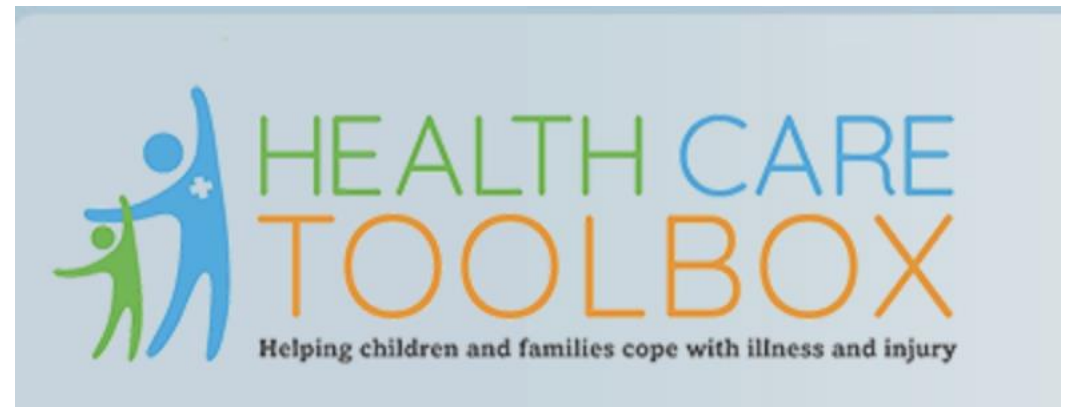


# OPEN ENDED QUESTIONS

- “In every situation, there are things that we cannot control. Sometimes this is difficult to acknowledge or accept. What are some aspects of this situation that you feel you cannot control?” “What are some aspects of this situation that you feel you can control?”
- “What strengths do you have that you can use to help comfort and take care of your child and yourself?”
- “Is there anything positive that you have learned about yourself that you can apply to this situation?”

# RESOURCES FOR PATIENTS AND CLINICIANS

- CHOP center for Pediatric Traumatic Stress
  - <https://www.chop.edu/centers-programs/center-pediatric-traumatic-stress>
- Healthcare Toolbox: a guide for professionals to help patients and families cope with illness and injury
  - <https://www.healthcaretoolbox.org>
- National Child Traumatic Stress Network
  - <https://www.nctsn.org>



# RESOURCES

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**QUESTIONS?**

