Trauma Informed Approach for Youth with Spina Bifida

Presented by:
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Disclosures

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• Do not intend to discuss commercial products or services.
• Do not intend to discuss non-FDA approved uses of products/providers of services.
Objectives

• Define trauma-related terms and highlight potential consequences of trauma for health and well-being from a bio-psycho-social perspective
• Identify risk factors for trauma in the population of youth with spina bifida, utilizing a developmental framework
• Outline a trauma-informed approach to include both definition and application to youth with spina bifida
• Outline examples of trauma-related needs among youth with spina bifida and describe appropriate, evidence-based interventions
• Provide the participants with relevant resources and agencies for use and support
Definitions

• Trauma: experience that harms physical & emotional well-being

• Traumatic stress: exposure to 1 or more traumas with development of reactions that persist and affect daily living, even after traumatic events end

• Post-Traumatic Stress Disorder (PTSD): Ongoing symptoms with specific American Psychiatric Association diagnosis
Youth with PTSD

Youth with Traumatic Stress

Youth with Traumatic Experiences
Prevalence

- Youth without disabilities have a 9% prevalence rate of maltreatment, while youth with a disability have a 31% rate (Sullivan & Knutson, 2000).
- In a population-based study (Houston) of maltreatment in children under the age of 2 with birth defects, children with spina bifida had a 58% greater risk of maltreatment than children with no birth defects (Van Horne et al. 2015).
- Of the children who are maltreated,
  - 64% had a disability (Sullivan & Knutson, 1998).
  - 99% of the perpetrators were well known to the child and the child's care providers (Baladerian, 1991).
  - Girls are at greater risk for sexual abuse and physical punishment, while boys are more likely to experience non-sexual assaults, accidents, illness, injury, and witnessing death (Tolin & Foa, 2006).
  - More girls meet criteria for PTSD than boys (Abram et al., 2004).
Psychological Trauma Types

• Natural Disasters
• Community Violence
• School Violence
• Domestic Violence
• Medical Trauma
• Refugee Trauma
• Traumatic Grief
• Neglect
• Physical Abuse
• Sexual Abuse
Epidemiology and Neuroscience

• ACE (Adverse Childhood Experience Study): High Risk Behaviors and Poor Health

• Studies on rodents and humans: impact of early adverse experiences on brain structures, HPA axis, genetic regulation
ACE Study

• Described relationship between extent of exposure to childhood physical, emotional, or sexual abuse and adult health risk behavior and disease
• Completion of questionnaire by almost 14,000 adults (ages 19-90) who had received a standard medical evaluation at a large HMO
• >50% of respondents reported one adverse exposure
• 25% reported >=2 exposures

ACE Study

- Logistic regression analyses controlling for age, gender, race, education: increased prevalence and risk (adjusted odds ratio) for smoking, obesity, depressed mood and suicide attempts as exposures increased.

- Persons with 4 exposures vs. 0: Odds Ratio of 12.2 for suicide attempts.

- Alcoholism, illicit drug use, history of sexually transmitted diseases increased with number of exposures.

- Strong dose-response relationship between number of exposures and each risk factor (p<0.001).
ACE Study

- Persons with 4 or more exposures had increased odds ratio for diabetes, hepatitis, chronic bronchitis or emphysema
- **Strong dose response relationship** between number of exposures and ischemic heart disease, cancer, chronic bronchitis or emphysema, hepatitis, jaundice, skeletal fractures, and poor rated self-health ($p<0.05$)
Perry’s Neurosequential Model

- Cortical
  - Empathy
  - Controlling yourself
  - Literacy
- Limbic
  - Emotional response
- Midbrain
  - Coordination
  - Movement
- Brainstem
  - Heart rate
  - Fight, flight, freeze

Experience Shapes Brain Architecture by Over-Production Followed by Pruning

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Neural Connections

birth   6 years   14 years

Atrophy and Dysfunction

- Corpus Callosum
- Prefrontal Cortex
- Hippocampus
- Amygdala
Glucocorticoid Receptor

- NR3C1
- Promoter region of this gene is methylated in individuals exposed to trauma
- In rodents: increased methylation in hippocampus of rats exposed to **low maternal care**; correlated with decreased hippocampal glucocorticoid receptor expression and increased glucocorticoid secretion
- In humans: **early life stress** during pregnancy associated with increased methylation in blood cells of newborns and appears to correlate with increased salivary cortisol stress responses
Heritable Change in Gene Function
No DNA Sequence Change

No methylation

Transcription factors can bind

Active gene ↑ Gene expression

Inactive gene ↓ Gene expression

Methylated DNA

Reduced binding of transcription factors
What Does Traumatic Stress Look Like?

• Depends on age and developmental level
• Interferes with youth’s daily life and ability to function and interact with others
• May interfere with youth’s ability to concentrate, learn and perform in school, be employed in future
• Burden for entire family
• May have a direct impact on youth’s brain and body
Consequences of Trauma that are Potentially Magnified in Youth with Spina Bifida

- Attachment difficulties
- Developmental Delay
- Nonverbal Learning Disability
- Memory impairments
- Executive function problems
- Depression
- Anxiety
Posttraumatic Stress Disorder (PTSD)

- Exposure to death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence
- Re-experience of the trauma event through nightmares, flashbacks, >1 month after original experience
- Avoidance/numbing symptoms, not thinking about event, memory lapses
- Arousal, increased irritability, sleep problems
- With negative thoughts and feelings

“RAAW”
# Trauma Symptoms across Development

<table>
<thead>
<tr>
<th>Preschool Children</th>
<th>Elementary School Children</th>
<th>Middle and High School Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Feel helpless and uncertain</td>
<td>• Become anxious and fearful</td>
<td>• Feel depressed and alone</td>
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<tr>
<td>• Fear of being separated from their parent/caregiver</td>
<td>• Worry about their own or others’ safety</td>
<td>• Discuss the traumatic events in detail</td>
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<tr>
<td>• Cry and/or scream a lot</td>
<td>• Become clingy with a teacher or a parent</td>
<td>• Develop eating disorders and self-harming behaviors such as cutting</td>
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<tr>
<td>• Eat poorly and lose weight</td>
<td>• Feel guilt or shame</td>
<td>• Start using or abusing alcohol or drugs</td>
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<tr>
<td>• Return to bedwetting</td>
<td>• Tell others about the traumatic event again and again</td>
<td>• Become sexually active</td>
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<tr>
<td>• Return to using baby talk</td>
<td>• Become upset if they get a small bump or bruise</td>
<td>• Feel like they’re going crazy</td>
</tr>
<tr>
<td>• Develop new fears</td>
<td>• Have a hard time concentrating</td>
<td>• Feel different from everyone else</td>
</tr>
<tr>
<td>• Have nightmares</td>
<td>• Experience numbness</td>
<td>• Take too many risks</td>
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<tr>
<td>• Recreate the trauma through play</td>
<td>• Have fears that the event will happen again</td>
<td>• Have sleep disturbances</td>
</tr>
<tr>
<td>• Are not developing to the next growth stage</td>
<td>• Have difficulties sleeping</td>
<td>• Don’t want to go places that remind them of the event</td>
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<tr>
<td>• Have changes in behavior</td>
<td>• Show changes in school performance</td>
<td>• Say they have no feeling about the event</td>
</tr>
<tr>
<td>• Ask questions about death</td>
<td>• Become easily startled</td>
<td>• Show changes in behavior</td>
</tr>
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</table>
Risk Factors for Youth with Spina Bifida

• Special needs in children with spina bifida may increase caregiver burden, including:
  • Physical disabilities
  • Intellectual disabilities
  • Mental health problems
  • Chronic physical illnesses

• Social isolation and low self-esteem

• Lack of knowledge about his/her body

• Youth < age 4 (includes “critical” developmental period, when it is hoped that youth with SB will receive early interventions to promote developmental gains)

https://www.cdc.gov/violenceprevention/childmaltreatment/riskprotectivefactors.html
Risk Factors Related to Interaction Between Youth & Caregivers

• Inadequate understanding of youth’s needs and developmental level (which may be inconsistent with chronological age)
• Inadequate parenting skills and parenting education
• Reduced mobility & increased reliance on others for intimate needs
• “Adherence” to routines set by caregivers may be reinforced
• Out-of-home placements
• Several outside caregivers may be involved over the long-term, and gain trust of youth and family
Risk Factors of Family Dynamics & Communities

- Reduced social experiences given time consuming care needs of youth and lack of accessibility in the community
- Family dissolution and conflict
- Parenting stress & poor communication within family
- Concentrated neighborhood
- High unemployment rates
- Community violence
- Myths about youth with spina bifida
Protective Factors that Reduce Risk of Trauma

- Supportive family environment and social networks***
- Nurturing parenting skills
- Stable family relationships
- Household rules and child monitoring
- Parental employment
- Adequate housing
- Access to health care and social services
- Caring adults outside the family that are role models or mentors
According to Substance Abuse and Mental Health Services Administration (SAMHSA), a trauma-informed approach is one that:

- **Realizes** the widespread impact of trauma and understands potential paths for recovery
- **Recognizes** the signs and symptoms of trauma in clients, families, staff, and others involved with the system
- **Responds** by fully integrating knowledge about trauma into policies, procedures, and practices
- **Seeks to actively resist** re-traumatization
Principles of a Trauma-informed Approach

• Safety
• Trustworthiness and transparency
• Collaboration and mutuality
• Empowerment
• Voice and Choice
• Culture, historic, and gender issues
Trauma-informed approaches to healthcare (1/2)
Trauma-informed approaches to healthcare (2/2)

- Health care providers caring for children with spina bifida can:
  - Incorporate an understanding of traumatic stress in their encounters with children with spina bifida and their families
  - Minimize the potential for trauma during medical care
  - Provide screening, prevention, and anticipatory guidance
  - Identify children and families in distress or at risk
Evidence-Based Practice Trauma Treatments

• “Evidence-based practice in psychology (EBPP) is the integration of the best available research with clinical expertise in the context of patient characteristics, culture and preferences” (APA, 2005)

• There are dozens of EBPs used to address the trauma needs of children. Some of the more commonly used EBPs include:
  • Child Parent Psychotherapy
  • Parent-Child Interaction Therapy
  • Trauma-focused Cognitive Behavioral Therapy
Trauma-informed Treatment: Core Components (cont.)

- Maintaining adaptive routines
- Parenting skills and behavior management
- Constructing a trauma narrative
- Teaching safety skills
- Advocacy on behalf of the client
- Teaching relapse prevention skills
- Monitor client progress/response during treatment
- Evaluate treatment effectiveness
Avrin, Charlton, & Tallant (1998) suggest the following modifications:

- Slow down your speech.
- Present information one item at a time.
- Be specific in making suggestions for change.
- Information may require a lot of repetition.
- Use visuals whenever possible to reinforce verbal messages.
- Ask for feedback after each item to ensure clear comprehension.
- Effective treatment for youth with spina bifida must include a variety of support and education services for caregivers.
Case Example: Presenting Concerns at a Medical Follow-up Visit

• Sally is a 10 year-old girl with spina bifida, Chiari II malformation, ventriculoperitoneal shunt, Non-Verbal Learning Disability and neurogenic bladder/bowel.

• Mother reports that Sally is not sleeping well at night, and is frequently wet now because she no longer wants to complete her usual clean intermittent catheterization. She also often complains of stomachaches.

• Mother adds that Sally appears withdrawn and does not follow directions when asked to do things. She notes that she has the most difficulty with Sally in the mornings, as she sends her off to school.

• Sally’s teacher reports that she has been more aggressive towards her classmates and is not trying her best with her classwork.

• Sally’s physician refers her for mental health treatment.
Case Example: Treatment

- In psychotherapy, Sally discloses that she does not like to go to school, because she does not like it when Joe tickles her “down there.” Joe is the school bus driver who has been molesting Sally for over a month. A CPS report is made.
- Sally participates in weekly individual and family therapy sessions using a modified version of TF-CBT and in a risk-reduction support group.
- Sally’s mother participates in collateral sessions, to learn positive parenting skills to support Sally at home.
- The therapist works closely with Sally’s school to make trauma-related modifications to her IEP, such as allowing time with the counselor, increasing structure, easing transitions, helping her identify interests, and offering a “safe space” where she can have personal time.
- After a year and a half in treatment, Sally no longer presents with her original symptoms, and functions well at home and at school.
Trauma Resources & Agencies

• Center on the Developing Child
  • Multidisciplinary team committed to driving science-based innovation in policy and practice

• International Society for Traumatic Stress Studies
  • Dedicated to sharing information about the effects of trauma and the discovery and dissemination of knowledge about policy, program and service initiatives that seek to reduce traumatic stressors

• National Child Traumatic Stress Network
  • Established by Congress in 2000, NCTSN is a collaboration of frontline providers, researchers, and families that combines knowledge of child development, child traumatic experiences, and evidence-based practices

• Substance Abuse and Mental Health Services Administration
  • SAMHSA is the agency within the U.S. Department of Health and Human Services that leads public health efforts to advance the behavioral health of the nation.
We can’t avoid pain but we can transform our response to it.
— Sharon Salzberg
References (1/2)


- California Evidence-Based Clearinghouse for Child Welfare (CEBC).

- https://www.cdc.gov/violenceprevention/childmaltreatment/riskprotectivefactors.html


References (2/2)