Trauma Informed Care for ID

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“Sit in the chair”

--Jerald Kay MD

Objectives

- Behavior: A form of communication
- TIC: Interventions should be universal
- Trauma experience based on developmental stage
- Interventions based on developmental stage

Concepts of TIC

- Safety
- Control
- The Individual

Categories/Stages

- Mild ID ~ adolescence ~ ages 12-17
- Mild/Moderate ID ~ school age ~ ages 6-11
- Moderate/Severe ID ~ young children ~ ages 2-6

How Trauma is Experienced

- Understanding the trauma experience at each developmental stage

Severe/Moderate ID: Trauma Experience

- <u>Can experience sights, sounds, and/or smells of environments as traumatic</u>
- Brains do not have the ability to calm fears; may have startle responses, night terrors, or aggression
- Think in images and are more likely to process trauma through play, drawing, story telling (rather than speech)

Trauma Experience: Severe/Moderate ID

- May regress behaviorally (enuresis/encopresis, thumb-sucking, fetal position, etc) in response to stress
- May not understand that some losses are permanent (Where's Russell?)
- Responses are behavioral or somatic
- Will SHOW you that he/she is upset, rather than tell you

Trauma Experience: Mild/Moderate ID

- Will take cues from others' non-verbal behavior regarding the seriousness of situations and how to respond
- May discount verbal explanations
- May over-estimate or under-estimate the seriousness of situations (knowledge is power)
- Use imagination to 'fill in the blanks' when limited or no information is given to them ("The staff left because of me") **(New staff: ADLs)**

Trauma Experience: Mild/Moderate ID

- Often react out of frustration and helplessness; responses can be impulsive, but are not necessarily intentional
- Can experience significant grief/loss reactions, even if loss expected (complicated grief processes)
- Need routine, predictability, and behavioral limits to re-establish feelings of safety and security (What/who is home base for you?)
- May imagine illness, injury or pain (physical or emotional) are punishments for past wrong doing

Trauma Experience: Mild ID

- Think logically about concrete events, but have difficulty understanding abstract or hypothetical concepts (“Don’t put trash in the trash can” “You can’t use the TV after 3:00”)

- One of the most important developments in this stage is an understanding of **reversibility**

Trauma Experience: Mild ID

- Sensitive to others' failures to protect them and can be unrealistic in their expectations of others' to make things better
- May act 'grown up' to protect others from distress (Family of 16 foster children)
- Are sensitive to being excluded from discussions about him/her (Email updates re: sensitive info)

Trauma Experience: Mild ID

- Are self-conscious regarding looking different or being isolated from peers
- Can experience significant pain, anger, or frustration when challenged to do something that was once routine (Rob: CP, non-ambulatory)
- Responses can include either withdrawing or acting out (intense anger, emotional outbursts, aggression etc) in response to stress
- Usually more concerned about the ‘here and now’ than about the future

Trauma Interventions

- Trauma interventions at each developmental stage

Trauma Interventions: Moderate ID

- Primary caregivers are the primary source of comfort for the individual
- Provide concrete explanations for what is happening, what will happen next, and for potentially traumatic sights and sounds in the environment (Norwegian ship wreck)
- Help identify and label what he/she may be thinking and remind him/her that others feel the same way (community)

Trauma Interventions: Severe/Moderate

- Provide him/her with a SAFE ZONE in the environment where everything is predictable, routinized and controlled
- Encourage expression of emotions through play, drawing or storytelling
- Provide and support consistent caretaking and reassurance
- Tolerate regressive symptoms in a time-limited manner

Trauma Interventions: Moderate/Mild

- Address distortions and magical thinking and help ‘fill in the blanks’ with realistic information
- Help them create a coherent story to tell others about when happened or what will happen “I gave my cell phone number out”
- Explain and talk about events before they happen; tell them what to expect

Trauma Interventions: Moderate/Mild

- Tell them it is normal and expected for them to feel afraid, angry or sad
- Help them acknowledge the bad things that have happened, and balance it with good
- Reassure him/her that they have done nothing wrong to cause the trauma
- Support activities that offer predictability, routine, and behavioral limits
- Ask open ended questions about what they are imagining

Trauma Interventions: Mild

- Help him/her understand it is common to react to anger by feeling numb or acting out
- Be open to expression of strong emotions
- Discuss the expected strain the trauma might have on relationships and the feelings of isolation
- Actively involve him/her in discussions and decisions that will impact him/her whenever possible

Trauma Interventions: Mild

- Help him/her anticipate challenges ahead and help problem solve preemptively to overcome the challenges
- Allow them time to acknowledge losses and to grieve (Bowling night is Tuesday)
- Help explore and discover things he/she can do looking ahead
- While discussing the future, don't dismiss concerns about the 'here and now'

“Ordinary” life event trauma could be:

- Feeling different
- Not being accepted
- Not being able to do what others do
- Moving to a new home or significant change at home
- Knowing that one has a disability and is “different” than others
- Not being listened to
- Being misunderstood
- Failing at a task
- Getting confused and overwhelmed

Factors that affect trauma outcome

- Duration
- Intensity of stressor
- Time of day
- Warning/ no warning
- Intentionality/preventability
- Scope/numbers affected
- Support system during and after traumatic event(s).

Risk Factors

- Previous history of trauma, stressors, abuse
- History or family history of mental illnesses
- Inherent resilience/vulnerability
- Substance abuse
- Difficult relationships/poor attachment to others; especially if the trauma has been caused by another person

TRAUMA

- Trauma syndromes have a common pathway
- Recovery syndromes have a common pathway
  - Establish safety
  - Reconstruct story
  - Restore connections

Taking sides

- Natural disaster
- Trauma of human design

At the moment of trauma

- Powerlessness
- Helplessness
- Complex and integrated systems of reactions encompassing both body and mind

Trauma Symptoms

- Three categories:
  - Hyperarousal
  - Intrusion
  - Constriction

Hyper-vigilance

- Permanent alert
- Startles
- Irritability
- Over reactions
- Insomnia
- Explosive aggression
- Disorganized

Hyperarousal

- Shattered fight or flight
- Chronic or random physiological phenomena may persist
- Repetitive stimuli: perceived as new and dangerous crisis increased arousal even during sleep
- Do you feel you need to defend yourself?

John

- 38 year old male
- History of Moderate ID, PTSD
- Severe and persistent emotional, physical and sexual trauma from birth to age 9 years
- Medication interventions

Intrusion

- Flashbacks (while awake)
- Nightmares (during sleep)
- Disturbing images/thoughts/fantasies
- Physical response (sweating, shaking, freezing, lashing out) to internal or external triggers that resemble the event
- As if time stops at the moment of trauma

Intrusion

- Relive trauma in THOUGHTS, DREAMS and BEHAVIORS
- Post traumatic behavior is often obsessive, repetitive and literal
- Theme is control is many aspects

Howard

- 54 year old male, history of moderate ID, schizophrenia (paranoid type)

- Hoarding
- Collecting
- Possessions

Constriction (Avoidance of Triggers)

- Avoids activities, places, people, things to keep from being reminded/"triggered" (avoidance can ripple out, become more and more removed from obvious triggers of incident)
- Can't remember important parts of the trauma
- Much less interest in significant activities
- Feeling detached from others; "freeze"
- Narrow range of emotions, numbness
- "Circle the wagons"

Constriction

- State of surrender
- Self defense shuts down
- Escapes not by action, but by altering state of consciousness
- Possible alterations in pain perception?

Julia

- 43 year old female
- Depersonalization Disorder
- Allegedly molested by father for 7 years

Tory

- 49 year old female
- History of Moderate ID, Schizophrenia (paranoid type), PTSD
- Flashbacks of sexual abuse
- Diaphoresis, ‘freezing’
- ‘Subvocalizations’
- Behavior support plan

At the moment of trauma

- Powerlessness
- Helplessness
- Complex and integrated systems of reactions encompassing both body and mind

Trauma Survivors

- Process the various participants (perpetrator, bystanders, etc)
- Survivor must:
- Acknowledge trauma (recognition)
- Institute action in the community (restitution)
- Rebuilds sense of order and justice

Healing

- Survivors hold the power to heal and recover
- Do not need to include perpetrators, family or others in the process
- The work is done in the room

Recovery

- Allow patients to save themselves
- Remember what your role is
- Not a savior or rescuer
- Facilitator, support
- Help reinstate renewed control
- The more helpless, dependent and incompetent the patient feels, the worse the symptoms become

The Contract

- Commitment to the future
- Commitment to moving forward
- Commitment to health and well being

- Clarify roles

John

- 32 year old male
- Profound ID
- No history mental illness
- No previous psychotropic medications
- Presents with aggressive behavior and assaults on several staff/peers

- Staff requests “Haldol and Ativan”

Addressing Medication Issues

- Seizure exacerbation: tegretol increase
- Intake for patient with DS: hearing aids
- Balance problems/proprioception: X rays
- Seroquel stopped working: weight gain
- Clonidine at bedtime

Toni

- 20 year old female
- History of Mild ID
- Recent months exhibited irritability, depression, insomnia, delusions
- 4 hospitalizations in 5 weeks
- Disrobing, verbally/physically assaultive, running into traffic, hypersexual

Toni

- Diagnoses
  - Major depressive disorder
  - Schizophrenia, paranoid type
  - Schizoaffective disorder, bipolar type
  - Obsessive compulsive disorder
  - Bipolar disorder
  - Autistic disorder
  - Aspergers syndrome
  - Post-traumatic stress disorder
  - Borderline Personality disorder
  - Antisocial Personality disorder

Toni

- Topomax
- Tegretol
- Lithium
- Geodon
- Abilify
- Haldol
- Trazodone
- Celexa
- Effexor XR
- Synthroid
- Tagamet
- Ativan
- Cogentin

- “Persons with physical and mental impairments are often granted a permanent visa to the kingdom of the sick.”

--Tighe, 2001

Intense rocking

- **Not “normal” for the patient with ID**
- Visceral pain
- Headache
- Depression
- Anxiety
- Medication side effects

Bobby: Impending Trauma

- 52 year old male with history of Profound ID, Autistic Disorder, cerebral palsy, and complete vision impairment
- For 4 months has exhibited agitation, verbal/ physical aggression, chanting, kicking, SIB and property destruction; has also begun gagging himself, and has shown a decrease in ADLs
- Decrease in appetite and weight loss of 13 pounds; began consuming inedible items, such as pieces of blankets, attends, and clothing
- Upon examination, rocking

Scope of the Problem

- Aggression is the **most common reason for MH referral** in the ID population
- It is multi-determined and influenced by biological, psychological, social and developmental factors (including trauma hx)
- Psychiatric and behavioral interventions must be tailored to needs of the individual

Impact of Aggression

- Individual
  - more restricted environment, unstable
  - reduced family involvement
- Caregiver
  - stress, burnout, injury
- Society
  - increased cost of hospitalization or incarceration

Aggression: A Behavior

- TRAUMA HISTORY
- Means of expressing frustration
- Learned problem behavior
- Expression of physical pain or acute medical condition
- Means of communication
- Signal of acute psychiatric problem
- Regression in situations of stress, pain, change in routine, or novelty

“I want you to work on Christmas Day”

- Ryan
- Trauma history
- PTSD
- Status/post kidney transplant (bilateral)

- Trauma Informed Care

Bio-Psycho-Social Developmental Formulation

Biological Aspects

- 85% have untreated, under-treated or undiagnosed problems
- worsened by restrictions on care (labs, office visit frequency and length)
- medications used in ways they were never intended, in unsafe ways, with abbreviated monitoring protocols

Most Common Causes of Behavioral Changes

- Pain (emotional and physical)
- Medication side effects
- Sleep disorders
- Psychiatric illnesses, including the after effects of trauma

Rule out Medical Issues First

- Organic
- Organic
- Organic
- Organic
- Then psychiatric...

A Distinguished Group

- “Antipsychotics are the most widely prescribed medications in individuals with intellectual disability even if schizophrenia and other psychotic disorders do not affect more than 3% of such population”
  - La Malfa G, Lassi S, Bertelli M, Castellani A. Reviewing the use of antipsychotic drugs in people with intellectual disability. Hum Psychopharmacol Clin Exp. 2006; 21:73-89.

Antipsychotics in ID

- They are often utilized for their general tranquillizing effect rather than their specific therapeutic purpose
  - “Antipsychotic drugs are often incorrectly used to manage or prevent all kind of behavioural problems or undiagnosed symptomatological clusters”
    - La Malfa G, Lassi S, Bertelli M, Castellani A. Reviewing the use of antipsychotic drugs in people with intellectual disability. Hum Psychopharmacol Clin Exp. 2006; 21:73-89.

Trauma: A Family Affair

- Laura, diagnosed with Down Syndrome
- New onset psychosis
- Risperdal/Buspirone trial begun in hospital
- Discuss with family the course of the illness and the reason for medications
- Tongue (mild dystonia??)

Primary Care/Preventive Care

Atypical presentations, behavioral and communication difficulties

Increased incidence of medical conditions of every organ system

Physician evaluation of pt with ID is similar to that of an patient with memory loss or delirium

Detective work, emphasis on observation, interpretation of behavioral presentations

Primary Care/Preventive Care

United States Preventive Services Task Force, 2007

Considered evidence based practices

Accepted as standard of care

“I’m safe now”

- Jeannette; trauma history
- GH staff; SSRI; psychotherapy
- New onset ‘unusual behavior’ rule out psychotic disorder (suspiciousness, aggression/property destruction with subsequent remorse, staring as if responding to internal stimuli)
- Resumed limited supervised relationship with mother; ‘How did you know it was time to see your mom again?’

Medication Side Effects

- Polypharmacy
- Autism: increased vulnerability to ataxia with benzodiazepines
- EPS: increased prevalence if muscular disorders
- Benzodiazepines (paradoxical, disinhibition, memory loss)
- Caution with medications affecting seizure threshold (bupropion, clozapine, other antipsychotics, etc)

Dave

- Aggression since April, 2013
- Leukocytosis (increased white blood cell count) on lab draw
- Clozapine 200mg at bedtime
- Depakote 500mg twice daily
- Presents in the fetal position

Gastrointestinal System

- More common in those with CP, spina bifida, inborn errors of metabolism
- GERD is very common
- GERD in institutional populations: 50% in those with IQ < 50 (Bohmer et al 2000)
- Recommendation: physicians should have low threshold for use of proton pump inhibitors

Gastrointestinal Conditions

- Upper GI bleeding: likely GERD
- Complicated by increased threshold to pain, decreased communication ability
- Male gender and history of pica are highest risk for acute abdomen
- H pylori: Type I carcinogen; 2X prev of gen pop

Matthew

- Second opinion (17 recommendations)

- Grief Loss
- 75 lb weight loss
- GI strictures/peptic ulcers

Summary

- **Trauma and Recovery (Judith Lewis Herman)**
- Behavior is purposeful
- Use the BPS-D Formulation to determine etiology
- Trauma recovery begins when the patient is able to tell his/her story

Summary

- Sit in the chair
- Assist the patient in telling their story
- Success is measured not in the form a diagnosis, a medication list, or a behavioral support plan

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