Agenda

• Introductions
• Learning Objectives
• Adverse Childhood Experiences/Events
• Trauma-Informed Care
• Window of Tolerance
• Post-Traumatic Stress Disorder
• Psychosocial Needs in Complex Care
  • Child/Youth ("Patient")
  • Parent/Caregiver
  • Sibling
  • Family Unit
• Hospitalizations & the CMC Family
• Mindfulness Meditation: Self-Compassion
• Questions/Discussion
Learning Objectives

• To introduce a trauma-informed framework to practice
• To develop a deeper understanding of the impact of living with a child with medical complexity on families
  • Parents/Caregivers
  • Patient/Child/Youth
  • Siblings
  • Family Unit
• To identify areas of need from a bio-psychosocial lens for families living with a child with medical complexity
Adverse Childhood Experiences

- Potentially traumatic events that occur in childhood
- Linked to chronic health problems, mental illness, and substance misuse in adulthood
- Impact brain development
- Common

(Centers for Disease Control and Prevention, 2023)
How Common are Adverse Childhood Events?

- ½ to 2/3 of Canadians experience an ACE prior to the age of 18 (1)
- 1 in 6 adults had four or more ACEs

(Giovanelli et al, 2019)
Trauma Informed Care

• Recognizes the pervasive nature of trauma
• Assumes an individual is more likely than not to have a history of trauma
• Promotes environments of healing and recovery to prevent re-traumatization
• Takes stance of "universal precaution"
• Creates policies and procedures to minimize barriers to services
• Integrates knowledge about trauma into staff training to prevent re-traumatization
Principles of Trauma Informed Care

- **Safety** – physical and emotional safety enhanced with welcoming common areas; privacy respected
- **Choice** – clear and appropriate message about rights and responsibilities
- **Collaboration** – treatment decisions are created by the service recipient and provider
- **Trustworthiness** – interpersonal boundaries, task clarity, consistency
- **Empowerment** – skill building with each contact

(CPI, 2021)
Don’t suffer alone
the definition of trauma is an overwhelming event experienced alone
Window of Tolerance

How Trauma Can Affect Your Window Of Tolerance

HYPERAROUSAL
Anxious, Angry, Out of Control, Overwhelmed
Your body wants to fight or run away, it's not something you choose - these reactions just take over.

WINDOW OF TOLERANCE
When you are in your Window of Tolerance, you find that you can deal with whatever's happening in your life. You might feel stress or pressure, but it doesn't bother you too much. This is the ideal place to be.

HYPOAROUSAL
Spacey, Zoned Out, Numb, Frozen
Your body wants to shut down. It's not something you choose - these reactions just take over.

Working with a counselor can help you strengthen your window of tolerance so that you are more able to cope with challenges.

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HYPERAROUSAL
Use mindfulness, grounding, Breath work
Overreactive, unclear thought, Emotionally distressed
Can't calm down

WINDOW OF TOLERANCE
The body is in its optimal state, Can access both reason and emotion. Mentally engaged

HYPOAROUSAL
Use mindfulness, breath work, physical activity
Depressed, lethargic, numb, unmotivated
Shutting Down

Can't calm down

Can't calm down
Post-Traumatic Stress Disorder

- Traumatic Experience
- Post-Traumatic Stress Disorder
- Ongoing fear of (past) threat in the here and now
- Building Block Effect
  - The more event types, the greater the likelihood of PTSD
  - Every time you add a traumatic event, the hot memory grows (fear network expands)
  - "What fires together wires together"
Post-Traumatic Stress Disorder (PTSD)

"Exposure to actual or threatened death, serious injury or sexual violation."

Exposure results from one or more of the following:

1) individual directly experiences the traumatic event
2) witnesses the traumatic event in person
3) learns the traumatic event occurred to a close family member or close friend
4) experiences repeated or extreme exposure to aversive details of the traumatic event"

(American Psychiatric Association, 2023)
Adaptive Responses

Hyperarousal Continuum

- Vigilance
- Resistance
- Defiance
- Aggression

Dissociative Continuum

- Avoidance
- Compliance
- Dissociation
- Fainting

(Perry, 1995)
## Adaptive Responses

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The Family of CMC
One Care Map
Parent/Caregiver
Impact

- Relationships
  - Family
  - Friends
  - Community
  - School
- Sense of Self/Identity
- Financial
- Safety
- Mental Health
- Religion/Spirituality
- Ability
- Independence
- Control
- Loss of future
- “Normalcy”
- Logistics
- Hopes and wishes
- Support Network
Parenting Themes: Newborn/Toddler

- Language/Cares
- Grief
- Mental Health (Post Partum – Depression, Anxiety, Psychosis)
- Loss of Idealized Child or Birth Experience
  - Not a Social Media Moment
- Pregnancy History
- Toddler’s behaviour and medical trauma
- Navigating development
Parenting Themes: School Age

- Transfer of Services
- New Team
- Managing
- More Care Providers
- Stress
- Grief
- Competing Parenting Needs
- Multifactorial Treatment Adherence
- Medical Trauma
- Kids starting to ask more questions and opinions about care
Parenting Themes: School Age & Youth

- Illness Narrative (Identity)
- Feel Unwell
- Fair World Belief Challenged
- Body Integrity
- Opportunity for Normative Experiences & Inclusion
- Education & Friendships
- How to Parent this Child?
- Protection
- Financial
- Parent Sense of Self
Parenting Themes: Adolescence

- Transition
- Independence
  - Knowing their Care
  - Relationship & Interface with Health Care and Health Advocacy
- “Normative Goals”
  - Dating & Personal Relationships
  - Post Secondary & Work Experience
  - Developmental Disability
- Grief & Loss for Parent
  - Teams
  - Future Thinking
- Push & Pull
Parent/Caregiver Challenges

- Losing & Starting Over
- Triggering Initial Trauma
- Future
- Relationships
- Fragmentation of Care
- Grief
- Trauma
- Family: Parent, "Patient"/Client, Sibling
Couple Relationship

- Pre-existing Couple Stressors and Dynamics
- Parenting & Familial Norms
- Coping as Couple (or Co-Parents) and as an Individual
What do parents of CMC manage?

• Sleep deprivation
• Witnessing acute, life-threatening events
• Providing care to own child
• System stressors (paperwork; navigation)
• Home supports under stress (groceries, laundry, ordering supplies)
• Family/friends do not understand
• Loss of predictability
• Loss of previous social, emotional, and recreational opportunities
• Isolation
• Distance from home
• Financial strain
• Stress
• Life in survival mode – impacts relationships, health and mental health
• Vicarious traumatization (code blue; code white)
• Medical fragility – hospitalizations ++++
Child/Youth ("patient")
Children and youth may experience psychological and physiological responses to:

- Pain
- Injury
- Serious illness
- Medical procedures
- Invasive or frightening medical treatment experiences

(ChOP, 2022)
The Patient

- Relationships
  - parents, siblings, extended family, peers, teams, school, etc
- Capacity, ability, pain & symptoms
- Emotions
- Communication
- Behaviour
- Independence
- Opportunity for Normative Experiences & Inclusion
- Respite
- Development
- Time at Home vs Hospital
Joys & Struggles of Siblings
Siblings

- Joys
  - Share home, experiences that no one else has
  - Closeness, love, intimacy, best friend
  - Protection
  - Family relations after parents are gone

- Struggles
  - Equitability/fairness
  - Juggling for ‘favorite child’ status
  - Sharing parental emotional and physical resources
  - Bullying, victimization
  - Differing personalities
  - Relationships within the family unit (subunits)
  - Fit within the family

"What causes sibling rivalry?"
"Having more than one kid."

Tim Allen
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Family Unit
Family

- Time spent together
- Balancing pre-existing conflicts
- Pre-existing roles and dynamics
- Social Location
- Space
- “Trapped”
- Delays in learning strategies
- Social Determinants of Health
Hospitalizations for Families

- Where do parents sleep?
- Where do parents eat?
- Where do parents shower?
- Where can parents be alone?
- How are children resourced? 1:1; 2:1; 3:1
- What happens to siblings?
- Who can visit?
“The expectation that we can be immersed in suffering and loss daily and be untouched by it is as unrealistic as expecting to be able to walk through water without getting wet”

(Remen 1996)
Mindfulness Meditation
Self-Compassion

- Exercise: How Would You Treat a Friend
What to do?
What can be done?

Tune in to: Lessons Learned: Patient, Sibling, and Parent Psychosocial Care in Complex Care
June 1, 2023
“What we don’t need in the midst of struggle is shame for being human”

Brene Brown
Presentation Resources

• Zlodre, Natalie. (2019). Trauma Counseling for Frontline Workers; *Sick Kids Centre for Community Mental Health*. 