Lessons Learned:
Patient, Sibling, and Parent Psychosocial Care in Complex Care

Project ECHO – Core Competency

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Agenda

• Introductions
• Parenting a Child with Chronic Illness
• Social Work & Complex Care
• Mental Health & Social Work
• Caring for the Caregiver (C4C)
• Therapeutic Relationship
• Grounding & Trigger Management
• Family Systems Theory & Attachment
• Self-Compassion
• Boundaries
• Setting Colleagues Up for Success
• Questions/Discussion
Parenting a Child with Chronic Illness

Health Outcomes of Parents of Children with Chronic Illness: A Systematic Review and Meta-Analysis

Liel N Cohn 1, Petros Pechivanoglou 2, Yuna Lee 3, Sarjay Mahant 4, Julia Orkin 5, Alanna Marson 6, Eyal Cohen 7

Abstract

Objective: To assess health outcomes of parents caring for children with chronic illnesses compared with parents of healthy children.

Increased maternal new-onset psychiatric disorders after delivering a child with a major anomaly: a cohort study

B Rotberg 1, E Horváth-Puhó 2, S Vigod 3, J G Ray 3, S, H T Sørensen 2, 6, E Cohen 2, 3, 7

Abstract

Background: The birth of a child with a major congenital anomaly may create chronic caregiving stress for mothers, yet little is known about their psychiatric outcomes.
“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
Role of Social Work in Complex Care

Responsibilities

• Crisis Intervention
• Complex child protection/ethical consultation
• Complex resource navigation
• Complex social advocacy
• Psychotherapy (inpatient & outpatient)
• Palliative/end of life work
• Transition support
• Funding applications
• Psychoeducation for staff
• Consulting/supporting team
• Attending multidisciplinary clinic visits
Mental Health & Social Work

- Guiding Principles
  - Strength Based
  - Trauma Informed
  - Anti-Oppressive
  - Anti-Colonialist
- Assessment
- Intervention
  - Narrative Therapy
  - Emotion Focused Therapy
  - Internal Family Systems Therapy
  - Cognitive Behaviour Therapy
  - Dialectical Behaviour Therapy
  - Mindfulness Self Compassion
  - Family Therapy

Mind Full, or Mindful?
Caring for the Caregiver (C4C): An integrated psychiatric care model to improve caregiver mental health

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C4C Study: Current SK CC Mental Health Model

C4C Step | Service | Provided by
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Step 1: Early identification of distress | Support: Monitoring, education, information, self-care, referrals to resources as needed | Nurse practitioners and physicians in complex care program in collaboration with psychiatrist and social workers
Step 2: Social work assessment, intervention and psychotherapy | Therapy: Strength-based psychotherapy for individuals, couples, and families, mental health assessment and complex system navigation (including linkage to community resources, therapists and family doctors)* | Social workers in complex care program
Step 3: Psychiatric care for caregivers | Psychiatry: including psychiatric/diagnostic assessment, short term interventions, medication initiation and monitoring, psychotherapy, referrals to community resources, liaison with family doctors, therapists, and psychotherapists, and psychoeducation* | Psychiatrist

Clinical collaboration and case discussion
Clinical collaboration and case discussion occurs through partnership between the psychiatrist and the complex care team during weekly rounds and one-on-one consultation

*Previous supports continue to be provided
C4C Study: Current SK CC Mental Health Model
Therapeutic Relationship

- Stabilize the de-stabilized client
- Access the “general factor” of therapy
  - Support
  - Connection
  - Validation
  - Atunement
  - Compassion
- Use therapeutic relationship to process unprocessed content
Increase Emotional Regulation Skills

• Grounding
• Relaxation
  • Progressive
  • Breath Based
  • Within Session
• Mindfulness
• Emotional Discrimination
Grounding

- Mental Grounding
- Physical Grounding
- Soothing Grounding

(Najavits, 2001)
Trigger Management

- Detection of triggered states
- Psychoeducation around distress reduction behaviours
- Harm reduction
  - Delay as long as possible
  - Do as little as possible
  - Replacing/distracting
- ReGAIN for triggered states

(Briere & Brach)
F-Words in Childhood Disability

- Function
- Family
- Fitness
- Fun
- Friends
- Future
Child/Patient

- Child Life Specialists
- Teachers
- Therapeutic Clowns
- Art Therapy
- Music Therapy
- Consultation Liaison Psychiatry
- Abilities
- Social Work
Social Work & Siblings

- Mental Health
  - With the sibling, parent, family
  - Assessment, treatment/intervention
  - Virtual and In person
- Parenting children with different needs
- Partnership with others
  - Music & Art Therapists
  - Child Life Specialists
  - Infant Development
  - Children’s Treatment Centres
  - Care Coordinators
  - Rehab Staff
  - Mental Health Staff
  - Extended family
  - Schools
  - Psychiatry
  - And more!

(Palacio 2017)
Family Systems Theory

• What is a family?
• Family Systems Theory
  • Context
  • Life Cycle
  • Construct/meaning
  • Values
  • Communication Patterns
  • Family Identity
• Attachment
Strategies

- Limits
- Boundaries
- Validation
- Emotion Coaching
“I’ve learned that people will forget what you said. People will forget what you did, but they will never forget how you made them feel”

Maya Angelou
“Self Compassion is the Antidote to Empathy Fatigue”  
(Neff 2021)
Now What: Self Compassion

• **Self Compassion**: “Treating ourselves with the same kindness and understanding as we would treat a dear friend when these things go wrong”

• **Universal expressions of compassion**:
  - Warm gaze
  - Soothing touch
  - Gentle Vocalization

• **Merits of Self-Compassion**
  - Increases in Well-Being
  - Improved affect
  - Reduced Stress & Shame
  - Physical Health Benefit
  - Quality Relationships

• **3 Components of Self-Compassion**: Kindness, Common Humanity, Mindfulness (Neff 2003)
“One of the things that self compassion provides for caregivers is the ability to do our work without getting so drained, without getting so exhausted, and really importantly, the ability to take satisfaction in our work”

Kristin Neff
Mindfulness Self-Compassion

- Nurturing
- Fierce

Yin and yang self-compassion:
Using caring force to change ourselves and our world

Yin:
- Comforting
- Soothing
- Validating

Yang:
- Protecting
- Providing
- Motivating

What are Boundaries?

• “something that indicates or fixes a limit or extent”
  • (Merriam-Webster, 2019)

• “Personal **boundaries** are guidelines, rules or limits that a person creates to identify reasonable, safe and permissible ways for other people to behave towards them and how they will respond when someone passes those limits”
  
  (Wikipedia, 2019)
Why are they important? Why are we talking about them?

- Set expectations
- Create safety & trust
- Respect
- Vulnerable State: families might be more susceptible to boundary crossing
- Snowballing
Tips to Set You & Your Colleagues Up for Success

• Consistency
• Under Promise, Over Deliver
• Say No
  • Creates boundary and with compassion
  • Kind and firm
  • Creates safety for speaker and listener
• Validate the Feeling
• *The Body Keeps the Score* – Dr. Bessel Van Der Kolk
  
  • “Being traumatized means continuing to organize your life as if the trauma were still going on—unchanged and immutable—as every new encounter or event is contaminated by the past.” (p53)
  
  • “Traumatized people chronically feel unsafe inside their bodies: The past is alive in the form of gnawing interior discomfort. Their bodies are constantly bombarded by visceral warning signs, and, in an attempt to control these processes, they often become expert at ignoring their gut feelings and in numbing awareness of what is played out inside. They learn to hide from their selves” (p97)
  
  • “We have learned that trauma is not just an event that took place sometime in the past; it is also the imprint left by that experience on mind, brain, and body. This imprint has ongoing consequences for how the human organism manages to survive in the present. Trauma results in a fundamental reorganization of the way mind and brain manage perceptions. It changes not only how we think and what we think about, but also our very capacity to think.” (p21)
Trauma Sensitive Mindfulness
Thank You!

Questions/Discussion