Caring for a Child with Medical Complexity

Dr. Catherine Diskin
I (we) would like to begin by acknowledging the land on which SickKids operates. For thousands of years it has been the traditional land of the Huron-Wendat and Petun First Nations, the Seneca, and most recently, the Mississaugas of the Credit River. Today, Toronto is home to Indigenous Peoples from across Turtle Island. SickKids is committed to working toward new relationships that include First Nations, Inuit, and Métis peoples, and is grateful for the opportunity to share this land in caring for children and their families.

Art by Emily Kewageshig
Mitigating potential bias

I work in an academic institution as part of a multidisciplinary team caring for CMC

No commercial conflicts of interest to disclose

I want questions
Learning Objectives

Define the population of CMC and their unique care needs

Identify the challenges of care delivery for this population from the perspectives of patients, their families, and the health-care system

Describe a care model for CMC
CMC: A Definitional Framework

**HEALTH CARE USE**
- High resource utilization
- Necessitating involvement of multiple service providers

**NEEDS**
- Substantial family-identified needs
- Significant impact on family (e.g., financial burden)

**FUNCTIONAL LIMITATIONS**
- Severe
- Often associated with technology dependence

**CHRONIC CONDITION(S)**
- Diagnosed or unknown but suspected
- Severe and/or associated with medical fragility
Standard Operation Definition for CMC

To be eligible for Complex Care for Kids Ontario, the child must:

- Be under 18 years of age.
- Meets one criterion (indicated by a check box) from four of the five categories below.
- Medically complex child/youth not currently being followed by a multi-disciplinary team (e.g., diabetes team, cystic fibrosis, or neuromuscular clinics). Rather, child/youth should continue to be followed in their current team rather than (individual exceptions aside) referred to the Complex Care for Kids Ontario.

**TECHNOLOGY DEPENDENT AND/OR USERS OF HIGH INTENSITY CARE**

- Child is dependent on mechanical ventilators, and/or requires prolonged IV administration of nutritional substances or drugs and/or is expected to have prolonged dependence on other device-based support
- Child has prolonged dependence on medical devices to compensate for vital bodily functions, and requires daily/near daily nursing care
- Child has any chronic condition that requires great level of care such as:
  - Child is completely physically dependent on others for activities of daily living (at an age when they would not otherwise be so dependent)
  - Child requires constant medical or nursing supervision or monitoring, medication administration and/or the quantity of medication and therapy they receive

**FRAGILITY**

- The child has severe and/or life-threatening condition
- Lack of availability and/or failure of equipment, technology, or treatment places the child at immediate risk resulting in a negative health outcome
- Short-term changes in the child’s health status puts them at immediate serious health risk
  - For example: an intercurrent illness
- As a consequence of the child’s illness, the child remains at significant risk of unpredictable life-threatening deterioration, necessitating round-the-clock monitoring by a knowledgeable caregiver
- Likely to experience exacerbation of chronic condition necessitating assessment by a healthcare provider in a timely manner
**CHRONICITY**

- The child’s condition is expected to last at least six more months
- The child’s life expectancy is less than six months

**COMPLEXITY**

- Involvement of at least five healthcare practitioners/teams and healthcare services are delivered in at least three of the following locations:
  - Home, School/Nursing school
  - Hospital
  - Children’s Treatment Centre
  - Community-based clinic (e.g., doctor’s office)
  - Other (at clinician’s discretion)
- The family circumstances impede their ability to provide day-to-day care or decision making for a child with medical complexity
  - For example, the primary caregiver and/or the primary income source are at risk of not being able to complete their day-to-day responsibilities

**GEOGRAPHY**

- Child meets criteria for at least three of the four previous categories, and has significant challenges to seek appropriate medical services based on rurality or access
Neonatal mortality rates (Canada)
Under five mortality rate (Canada)
*CA = Congenital Anomalies

Russell Wilkins (Health Information and Research Division. Statistics Canada)
Children’s Health Care Needs

All Children

Short Interval Acute Care

Special Health Care Needs

CMC

Regular Health Care Providers

Specialized Health Care Providers

Adapted from Robert Armstrong. The Challenge of Caring for Canada’s Children and Youth. CAPHC 2004
The Rise In Chronic Conditions Among Infants, Children, And Youth Can Be Met With Continued Health System Innovations

<table>
<thead>
<tr>
<th>Main condition groups</th>
<th>Health condition examples</th>
<th>Drivers</th>
<th>Change in services</th>
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<tbody>
<tr>
<td>Individually rare, usually serious conditions</td>
<td>Childhood cancer, cystic fibrosis, congenital heart disease, and complications from premature births</td>
<td>High mortality drops in mid-twentieth century</td>
<td>Complexity of care is beyond the scope of primary care physicians for these rare conditions</td>
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<td>Common chronic health conditions and developmental and mental health conditions</td>
<td>Asthma, overweight and obesity, attention deficit hyperactivity disorder, and autism spectrum disorders</td>
<td>Highly specialized, technology-enhanced care has led to lower mortality with varying morbidity</td>
<td>Care has become multidisciplinary and concentrated in specialty centers</td>
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<td>Dramatic growth in prevalence has risen since the 1980s</td>
<td>Likely environmental changes, particularly social environments and potentially environmental toxins; some genetic basis; greater emphasis on screening and identification</td>
<td>Increasing prevalence has overwhelmed the supply of pediatric specialists</td>
<td>Care has become decentralized, focused in pediatric primary care; also, some community-based care through schools and regional early-intervention programs</td>
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Medically fragile and technology dependent children

- Increasing in number
- Living longer
- Living at home

- <1% of all children
- 1/3 of paediatric healthcare spend
- 56 x as many healthcare resources as well children

Cohen, 2012; Srivastava, 2005; Dosa, 2001; Slonim 2003
THE EXPERIENCE OF CMC & THEIR FAMILIES
The child with medical complexity

Represents ¼ of paediatric deaths

More likely to end up in ICU

More likely to have “preventable” admissions (e.g., inadequate care coordination)

Quick readmission - 25% of CMC are readmitted within 30 days of discharge (78% of CMC are readmitted within 2 years)

Have longer hospitalizations (8x)

Medical error more common
A year in the life

An average of 13 physicians representing 6 specialties

CMC had 4X more specialty clinic visits compared to a child with single disease

6 primary health care visits in 1 year

Over a 2-year period:
- 2/3 of CMC had at least 1 ED visit
- 1/3 had at least 1 hospital stay
- CMC with technology had more frequent ED & Hospitalizations
ONE FAMILY’S EXPERIENCE

EDUCATION
- Enhanced learning support
- Augmentative communications program/equipment

VISION THERAPIST

SCHOOL

HEALTHCARE
- Vision impairment clinic
- Paediatrician
- Family physician
- Neurology
- Gastro-intestinal clinic
- Dental clinic
- Ophthalmology clinic
- Pharmacy
- Pump clinic
- Orthotist
- Neuromotor clinic
- Orthopaedic surgeon
- Neurosurgeon

COMMUNITY
- Adapted van
- Wheelchair accessible transit
- Funding agencies
- House accessibility renovations
- Equipment suppliers

SOCIAL SUPPORTS
- Cerebral Palsy Association
- Canadian National Institute for the Blind
- Respite support
- Camp Easter Seals
- Abilities Society
- Summer aide

Source: Kidshealthalliance.ca
<table>
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<tr>
<th>MONTH</th>
<th>NIGHTS SPENT IN HOSPITAL</th>
<th>OUTPATIENT VISITS</th>
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<td>July</td>
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FAMILY OF CMC

Caregiver Responsibilities
Health
Time
Financial Strain
Relationship
On weekdays during the day (6am – 6pm), 55% of caregivers provide care for 8 hours or more.

On weekday evenings and nights, 50% of caregivers provide care for at least 6 hours.

3 – 21 hours per week providing direct care.

1 – 6 hours per week on care coordination.
Family of CMC

Caregiver Responsibilities

- Health
- Financial Strain
- Time
- Relationship

Health outcomes worsen incrementally with complexity of child

Experience

- 20–25% decrease in general health
- Grief and PTSD
- Reduced overall quality of life
- Are more likely to report mental and physical health problems
- 20–25% decrease in the general health of caregivers
Caregiver Responsibilities

Health

Time

Financial Strain

Relationship

FAMILY OF CMC

- Poorer Mental Health: more anxiety and depression
- Mothers of children with congenital anomalies - greater risk of CVS disease and mortality
- Need for targeted interventions
Elevated risk of poorer mental health particularly the weeks to months following the cardiac surgery

30% meeting criteria PTSD, 25-50% reporting anxiety and depression

Urgent need for additional research for further defining the course, screening and interventions
Caregiver Employment

- 75% of caregivers and 53% of spouses experience employment loss
- 33% experience a negative care outcome

FAMILY OF CMC

- Out of pocket expenses
- Multiple applications for funding
FAMILY OF CMC

Caregiver Responsibilities

Health

Time

Financial Strain

Parent – Parent
Parent – child with medical complexity
Parent – well-children
Well-sibling – child with medical complexity
Nuclear family and broader family
Social relationships
Intersectionality
• Asserts that people are often disadvantaged or privileged by multiple sources of identity
• Intersectionality recognizes that identity dimensions do not exist independently of each other, often creating a complex convergence of disadvantage and privilege

(Sojourner Truth 1851; Kimberlé Crenshaw 1989)
Intersectional Lens: Social Determinants of Health
Impact of Epilepsy on Children and their families

- Various lines of inequities and identity can intersect and reinforce each other
- Health disparities experience by individuals/families with disabilities is worsened by low in-come status, race, education, etc.
- Disadvantage is almost always multi-dimensional

Kerr et al, 2011
The Interwoven Nature of Medical and Social Complexity in US Children

Jay G. Berry, MD, MPH; Debbi Harris, MA, MS; Ryan J. Coller, MD, MPH; et al
A lens, a prism, for seeing the way in which various forms of inequality often operate together and exacerbate each other.

Kimberlé Crenshaw, 2020
COMPLEX CARE PROGRAM AT SICKKIDS
Complex Care Kids Ontario

Established June 2015 – Ontario Ministry of Health & Long-term Care

- **Mission:**
  - Province-wide access to integrated care and coordination for children/youth who persistently demonstrate the most complex medical care needs

- **Strategic Outcomes:**
  - Improved child/youth & family experience & outcomes
  - Improved collaboration and communication between providers
  - Improved system efficiency, effectiveness and sustainability
Our model of care

Family understood to be child’s primary strength and support

Foundation of care for CMC is families and providers working together in the best interest in the child

Families are full and equal partners in decision-making

Communication and information sharing is open and objective

Families understand health care system and the drives for health
Tenets of Trauma informed Care (TIC)

1. SAFETY
2. TRUSTWORTHINESS & TRANSPARENCY
3. PEER SUPPORT
4. COLLABORATION & MUTUALITY
5. EMPOWERMENT VOICE & CHOICE
6. CULTURAL, HISTORICAL & GENDER ISSUES

Adapted from the Substance Abuse and Mental Health Services Administration’s "Guiding Principles of Trauma-Informed Care"
Overview

• >650 medically complex, technology dependent children
  ✓ Intensive service coordination and care delivery
  ✓ Regional partnerships
  ✓ Inpatient/outpatient collaboration
  ✓ 9 satellite clinics
  ✓ Bridge between tertiary, community and primary care

GOAL:
Every child with medical complexity can reach an integrated program within 100km of their home.
Standard Operation Definition for CMC

- Technology Dependent and/or Users of High Intensity Care
- Fragility
- Chronicity
- Complexity
- Geography

Complex Care Kids Ontario, Provincial Council for Child and Maternal Health
Partnership NP model

All patients have the following support through the program:

✓ Individualized integrated care plan and team
✓ Nurse practitioner model liaising with home-based care
Objectives of a Complex Care Clinic

Integrated Care

Communication and Information Sharing

Advocate, Mentor, Support

Care for the Whole Family

Care Coordination

Proactive Care

Establish Clear Goals of Care

Provincial Council for Maternal and Child Health PCMCH Complex Care of Kids Ontario Strategy 2017
Patient-centered care

• Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions

• The patient and caregiver are central in decision making

Committee on Quality Health Care in America, 2001
“Something that indicates or fixes a limit or extent”  
(Merriam-Webster, 2019)

“What are boundaries?”

“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)
<table>
<thead>
<tr>
<th>Boundaries</th>
<th>Expectations</th>
<th>Safety &amp; Trust</th>
<th>Respect</th>
<th>Predictability</th>
<th>Vulnerability</th>
<th>Equilibrium</th>
<th>Personal Health Information</th>
<th>Impact of Illness</th>
<th>Snowballing</th>
<th>Helping Professions</th>
</tr>
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</table>
How do we know we are being listened to?

What can you do? Listen.
Complex Care Service  
Paediatric Medicine  
Care Plan  
Printed 2015-06-03

TRANSFER/DISCHARGE:  
Patient Discharged on 2009-03-27

DIAGNOSIS:  
Primary  
Probable metabolic/genetic disorder  
Other  
Seizure Disorder  
cortical visual impairment  
Chronic Otitis Media  
S/P tympanostomy tube insertion 2010  
S/P tonsillectomy and adenoidectomy 2010  
right choanal atresia  
chronic lung disease  
obstuctive sleep apnea and central hypoventilation  
Repaired tetralogy of fallot  
Dysmotility (reverse peristalsis)  
Oral motor feeding problems/aspiration from above  
Chronic Constipation  
Right hip subluxation  
scoliosis  
Alopex dermatitis  
Transfusion dependent anemia

CARE PLAN:  
OVERVIEW  
Mickey loves to go for rides in her motorized wheelchair and watch Harry Potter movies. She loves attention from her older brother and younger sister. She likes holding her cat (muffin) and listening to “Cold Play” on her iPod. She is the happiest when outside in the park, in the pool or spending time with her family.

ALLERGY:  
Penicillin.

COMPLEX CARE CONTACTS:  
Sherri Adams  
Paediatric Medicine  
NP - Paediatrics  
Phone: 416-613-5787  
Pager: 416-370-5296

PATIENT CARE GOALS:  
Dr. Eyal Cohen  
Paediatric Medicine  
Paediatrican  
Phone: 416-813-7654 ext 202626
Clinical care of CMC: The Challenges

- Multiple conditions
- Lack of evidence – hard to be an expert
- Family experience
- Conflict
- Witness of suffering
- Shared decision making – true partnership
- Compassion fatigue and burnout
Unique Challenges of Care Providers

- Balancing their own personal struggles
- Pre-existing Systemic Issues
- Limits in terms of what can be offered to address challenges
- Self-Care
- Different Roles
  - Interprofessional
  - Transdisciplinary
  - Multidisciplinary
Staff wellness

- Safety
- Peer Support
- Collaboration and Mutuality
- Informal Supports
- Team meetings
- Peer Support
- Debrief
Tips to Set You & Your Colleagues Up for Success

✓ Consistency
✓ Under Promise, Over Deliver
✓ Follow the rules
✓ Say No
  - Creates boundary and with compassion
  - Kind and firm
  - Creates safety for speaker and listener
✓ Validate the Feeling
Building blocks of TIC: Intersectionality

Adapted from the Substance Abuse and Mental Health Services Administration’s "Guiding Principles of Trauma-Informed Care"
EVERY MOMENT & INTERACTION CAN BE AN INTERVENTION

A SPARKLE OR A LIGHTBULB ONE
HELPFUL & HEALING OR HARMFUL
EXPANDING OR RESTRICTING
TRAUMA-INDUCING OR TRAUMA-REDUCING
A TURN AROUND ONE
A SEED PLANTED
AN OPEN OR CLOSED DOOR
A SNAKE OR A LADDER
A RIPPLE OR A TIDE
ENRICHING OR CONstrictING

DR. KAREN TREISMAN
Final thoughts

We won’t always have the answer or a solution.

Acknowledging a family’s concerns and allowing them to talk about their experiences goes a long way.

Simply listening and being aware of the struggles these families go through can make a big difference.
References


References


