

Caring for a Child with Medical Complexity

SickKids

Dr. Catherine Diskin



Complex Care

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

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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



CMC: A Definitional Framework

HEALTH CARE USE

- High resource utilization
- Necessitating involvement of multiple service providers

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





G

- Severe
- Often associated with technology dependence

CHRONIC CONDITION(S)

- Diagnosed <u>or</u> 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

Question

Are there any questions about the definition for children with medical complexity?



Neonatal mortality rates (Canada)





Under five mortality rate (Canada)



*CA = Congenital Anomalies



Russell Wilkins (Health Information and Research Division. Statistics Canada





Adapted from Robert Armstrong. The Challenge of Caring for Canada's Children and Youth. CAPHC 2004 Regular Health Care Providers

Specialized Health Care Providers



EXHIBIT 1

Changing Epidemiology Of Childhood Chronic Conditions, Their Drivers, And Changes In Service Organization

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

The Rise In Chronic Conditions Among Infants, Children, And Youth Can Be Met With Continued Health System Innovations

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

Children with medical complexity are more likely to have preventable admissions to hospital

True or False?

Children with medical complexity are more likely to experience medical errors

True or False?

Most children with medical complexity are readmitted to the hospital within 2 years

True or False?



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









TIME AT HOSPITAL

July 2018 - June 2019

MONTH	NIGHTS SPENT IN HOSPITAL	OUTPATIENT VISITS
July		<u>*</u>
August		<u>*</u>
September		<u> * *</u>
October		
November		<u>*</u>
December		
January		<u> * *</u>
February		
March		<u> * * *</u>
April		
May		
June		<u>\$</u>

Caregiver Responsibilities

Health

Time

Financial Strain

Relationship

FAMILY OF CMC

Caregiver Responsibilities

Health

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FAMILY OF CMC

1 – 6 hours per week on care coordination

3 – 21 hours per week providing direct care

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

What is the percentage decrease in the general health of caregivers of children with medical complexity?

Experience

- 20 25% decrease in the general health of caregivers
- Grief and PTSD
- Reduced overall quality of life

Are more likely to report mental and physical health problems

Health outcomes worsen incrementally with complexity of child

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The Journal of Pediatrics Volume 218, March 2020, Pages 166-177.e2



Original Article

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

Liel N. Cohn ^{1, 2, 3}, Petros Pechlivanoglou PhD ^{2, 4}, Yuna Lee BSc ⁵, Sanjay Mahant MD, MSc ^{1, 2, 4}, Julia Orkin MD, MSc ¹, Alanna Marson MLIS ⁶, Eyal Cohen MD, MSc ^{1, 2, 4} A 🖾

- Poorer Mental Health: more anxiety and depression
- Mothers of children with congenital anomaliesgreater risk of CVS disease and mortality
- Need for targeted interventions

Caregiver Responsibilities

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FAMILY OF CMC

Journal of the American Heart Association Volume 6, Issue 2, 2 February 2017 https://doi.org/10.1161/JAHA.116.004862



SYSTEMATIC REVIEW AND META-ANALYSIS

Mental Health Among Parents of Children With Critical Congenital Heart Defects: A Systematic Review

Sarah E. Woolf-King, PhD, MPH^{*,1,2}; Alexandra Anger, RN-BSN^{3,4}; Emily A. Arnold, PhD²; Sandra J. Weiss, PhD, DNSc, FAAN³; David Teitel, MD⁴

- 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

Caregiver Responsibilities

Health

Time

Financial Strain

Relationship

FAMILY OF CMC

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

• Out of pocket expenses

Multiple applications for funding

Caregiver Responsibilities

Health

Time

Financial Strain

Relationship

FAMILY OF CMC

- Parent Parent
- Parent child with medical complexity
- Parent well-children
- Well-sibling child with medical complexity
- Nuclear family and broader family
- Social relationships

Reflection

• Share an example of how your team modified your care delivery and how it led to an improvement in the quality of life for a family

• Share the most important thing that you've learned from a caregiver of a child with medical complexity



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



JAMA Pediatrics

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







Kimberlé Crenshaw, 2020

A lens, a prism, for seeing the way in which various forms of inequality often operate together and exacerbate each other



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



Tenets of Trauma informed Care (TIC)



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





All patients have the following support through the program:

- Individualized integrated care plan and team
- Nurse practitioner model liaising with home-based care

Integrated Care

Communication and Information Sharing

Advocate, Mentor, Support Care for the Whole Family

Care Coordination

Proactive Care

Establish Clear Goals of Care

Objectives of a Complex Care Clinic

Provincial Council for Maternal and Child Health PCMCH Complex Care of Kids Ontario Strategy 2017

Patient-centered care

Committee on Quality Health Care in America, 2001)

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

"Something that indicates or fixes a limit or extent" (Merriam-Webster, 2019)



WHAT BOUNDARIES?



(Wikipedia, 2019)







THE HOSPITAL FOR SICK CHILDREN

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 tonsilectomy and adenoidectomy 2010 right choanal atresia chronic lung disease obstructive 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 Atopic 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 bother 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: 416-813-5787 Pager: 416-370-5296 Dr. Eyal Cohen Paediatric Medicine Paediatrician Phone: 416 813-7654 ext 202626

PATIENT CARE GOALS:

CLEAVER, WARD 555 UNIVERSITY AVE. TORONTO ON 416-813-5391 M1G2H3 0215785142



Clinical care of CMC: The Challenges

Compassion fatigue and burnout

with cost of suffering

Witness of suffering

Family experience

Conflict

Lack of evidence – hard to be an expert

Shared decision making – true partnership

Multiple conditions

Balancing their own personal struggles

Pre-existing Systemic Issues

Limits in terms of what can be offered to address challenges

Self-Care

Different Roles

Unique Challenges of Care Providers

- Interprofessional
- Transdisciplinary
- Multidisciplinary

Safety

Peer Support

Collaboration and Mutuality

Informal Supports

Team meetings

Debrief

Staff wellness

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"





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.



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