Care Coordination and Care Plans

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Learning Objectives

Describe challenges in care coordination for children with medical complexity (CMC) and their families.

Describe members of clinical team and role of key clinical worker.

Discuss the utility of care plans and care maps.

Review an approach to transition to adult care for CMC.
Children with Medical Complexity (CMC): A Definitional Framework

Cohen, E. et al., Pediatrics 2011

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

FUNCTIONAL LIMITATIONS
- Severe
- Often associated with technology dependence

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

CHRONIC CONDITION(S)
- Diagnosed or unknown but suspected
- Severe and/or associated with medical fragility
Children with Medical Complexity
Improved health care coordination models help CMC and their families:

- Get the care that they need
- Reduce the opportunity for health care error
- Improves their care experience
BARRIERS
BARRIERS

• Patient-centered barriers
• Family-centered barriers
• Barriers related to the health-care system
Patient-Centered

Physical Challenges

Logistical Challenges

Absence of care coordination

Lack of integrated care
Physical Challenges

- Patient-Centered
- Medical equipment
- Accessibility
Logistical Challenges

- Travel to appointments
- Interruptions to provide care
- Vehicle to support safe transportation
- Constant visualization of the child, may require another adult
Patient-Centered

- Absence of care coordination
- Lack of streamlined goals of care
- Poor communication between providers and teams
- Multiple appointments
Between primary care, tertiary care, home care, and community-based settings.
Family-Centered

Strain on caregiver health
Impact on siblings
Tension within parental relationship
Financial Burden
Many experience adverse mental and physical health effects.
Increased absenteeism from school, reduced participation in extracurricular activities, behavioural issues, and an unpredictable daily routine.
Stresses and worries, advocating for their child, financial concerns, and caring for other siblings can place strain on the relationship.

Family-Centered

Tension within parental relationship
Additional costs and reduced income as parents may change their working arrangements to provide care for their child.
System Barriers

- Lack of communication and integrated programs.
- Lack of family-centred care and partnership.
- Lack of communication between different professionals.
- Limited funding for Complex Care programs.
- Lack of transition programs from paediatric to adult care.
Coordinate multiple appointments in one day

Find child care for siblings

Reschedule nursing hours

Schedule time off

Book transportation
A Family’s Journey through a Hospital Visit

Scheduling Clinic Appts.

Travel & Parking

Registration & Check-in

Waiting Room

Multiple Care Provider Appts

Investigations

Travel Home

Source: Kids Health Alliance
Ensure all bags and equipment are packed in the car

Long commutes; must stop for suctioning

Appointment times too early for out-of-town patients

High cost of parking

Lack of accessible parking spots
A Family’s Journey through a Hospital Visit

Source: Kids Health Alliance
Difficulty finding clinic location

Repeating information

Lack of accessible doors, washrooms
A Family’s Journey through a Hospital Visit

Source: Kids Health Alliance
Long wait

Exposure to illness and infection

Agitation from multiple stimuli

Lack of accessible space
A Family’s Journey through a Hospital Visit

Source: Kids Health Alliance
Unprepared students

Repeating the story to multiple providers

Waiting for doctors or specialists to arrive
A Family’s Journey through a Hospital Visit
Anxious about results

Confusion with requisitions

Long wait

Issues with rescheduling appointments
A Family’s Journey through a Hospital Visit

Source: Kids Health Alliance
A Family’s Journey through a Hospital Visit

Source: Kids Health Alliance
What are the objectives of a Complex Care program?
Develop clear goals of care
Support holistic care for the whole family
Advocate for children and families
Deliver proactive care
Coordinate care
Facilitate communication
Integrate care
CCKO Functions of a Complex Care Clinic and Program Standard
INTEGRATED CARE

Contrast to “fragmented, episodic care”

Coordinated across team, organizations, systems

Encompasses unique child and family needs and preferences
COORDINATE CARE

Led by key clinical worker

Partnership with child and family
FACILITATE COMMUNICATION

Key worker facilitates access and communication

Complex Care Plan
DELIVER PROACTIVE CARE

Active identification of potential concerns and determining activities that will reduce the incidence or severity of the 'potential problem’

Screening, early intervention
Empower and support children and families over time, fostering their strengths without creating dependence.

Promote building capacity within the child/youth and family, and community teams.
DEVELOP GOALS OF CARE WITH THE CHILD AND FAMILY

Determining a child and family's overarching goals allows the health-care team to help meet these goals.
Understand the child/youth and family structure and current services in place as well as the strengths and needs of each child/youth and their family.
Who are members of a Complex Care Team?
Members of the Complex Care Team

- Nurse Practitioner (key clinical worker)
- Paediatrician
- Social Worker
- Registered Dietitian
- Program Coordinator
- Home and Community Care Support Services Coordinator
The key clinical worker is central to Complex Care programs. The worker is often a nurse practitioner whose primary responsibilities include:

- Being the primary point of contact for the child and family to address dynamic medical needs
- Developing longitudinal relationships to help ensure children and families goals are met and to focus on the child’s quality of life
- Coordinating care by facilitating inter-disciplinary collaborative care amongst a variety of settings
- Facilitates the development and management of the child’s Complex Care Plan in partnership with the family
- Engages other members of the care team as necessary
What is a care plan/shared plan of care?
Care Plans for CMC

- A written document that outlines major medical information and care needs for a specific child

- “A comprehensive compiling of the information, in partnership with the family, needed to support coordination of care for the multiple needs of an individual child or youth, and his or her family”

https://downloads.aap.org/AAP/PDF/Medical%20Home/Shared%20Plan%20of%20Care2.pdf
What do they do?

• Improve family-clinician relationships by enhancing/validating information exchange
• Support provision of family-centered care
• Provide information that enhances the care relevant to both medical and social needs of CMC
• Component of care coordination


To explore how parents and Health Care Providers (HCPs) of CMC perceive the usefulness of a care plan

Interviewed 15 parents
Focus Groups 15 HCPs
Outcomes

- Safety
- Efficient & Timely Care
- Caregiver Health & Wellbeing
- Care Coordination
- Patient & Family Centered Care
- Continuity of Care

Activating Factors

- Family to HCP
- Across HCPs
- Across Organizations
- Across Sectors

Characteristics

- Dynamic Document
- Shared Values
- Content

Quality of Care

Relationships ↔ Information Sharing

Comprehensive Care Places

- Safety
- Care Coordination
- Patient & Family Centered Care
- Continuity of Care
- Caregiver Health & Wellbeing
I think it’s a comprehensive road map, or Google map, Coles [Cliff] notes version for complex patients, instead of a thick chart. That summarizes where you’re at, and where you’re going, and who to contact...

(Health care provider)
Characteristics

Activating Factors

Comprehensive Care Places

Dynamic

Document

Shared

Values

Content

Relationships ↔ Information Sharing

I had this underlying anxiety that they weren’t going to listen to me, how am I going to get them to understand me. Okay, screaming isn’t working, what can I do to have them listen? That’s gone. [The care plan] sort of levels out the playing field. We’re both talking the same language. I may not have medical training, but I have this, I have this piece of paper. And we’re speaking the same language. And it gives me a level of comfort, it gives me a level of security.”

(Mother)

Credibility
Outcomes

Quality of Care

Safety
Efficient & Timely Care
Caregiver Health & Wellbeing
Patient & Family Centered Care
Care Coordination
Continuity of Care

Relationships ↔ Information Sharing

Family to HCP
Across HCPs
Across Organizations
Across Sectors

Comprehensive Care Places

Dynamic Document
Shared Values
Content

There is another benefit I wanted to add. When we are in the hospital and we see doctors for the first time [...] they start asking the parents questions. And I can’t tell you how many times I’ve had to give her medical history with all its gory details. And it’s extremely stressful for me. So this [the care plan] saves me from having to deal with that. [...] We all go through so much as parents, and we suffer a lot physically, emotionally, psychologically. So this document saves me.” (Parent)
Findings

- Care plans are a tool to build trust and relationships
- Family empowerment and credibility
- Starting point for HCPs
- United advocate
Where do care plans fit into care coordination?

1. Identify the needs and strengths of the patient and family
2. Build Essential Partnership
3. Create the Care Plan
4. Implement the care plan

Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs
Jeanne W. McAllister, BSN, MS, MHA, 2014
This report outlines the principles for the shared plan of care model and recommends core content for an integrated and comprehensive shared plan of care for children, youth, and their families.
Complex Care for Kids Ontario Standard:
Medical Care Plan

Version Date: May 9, 2017
The following are standard data elements to be included in a medical care plan:

- Child Identification
- Allergies/Reaction/Alerts
- Caregiver Names and contact
- Legal Guardian and contact
- Advance Directives (indicate documented decisions)
- Diagnosis
- Short Non-medical Description of the child
- Complex Care primary contacts: clinical key worker, physician

- ER Management
- Medication List
  - Scheduled and PRN Medication
  - Parenteral and/or G-tube feeds
- Growth parameters and unusual ‘normals’ in vital signs or physique

- Communication
- Technology/Technology Support
- Current issues (systems based)
- Adaptive seating
- Mobility aids
- What I want for my child (Commonly known as ‘Patient care goals’)

- Immunizations
- Signature (or electronic trail) of person updating content medical care plan Last updated (electronic trail sufficient if present)

- Contact List
  - Family Physician/Paediatrician
  - List of Physicians and Programs Followed at Tertiary Hospital or Community
  - Special Needs Strategy: Coordinated Service Planning Care Coordinator
  - LHIN Care Coordinators

Consider action list
DIAGNOSIS:
Primary: genitourinary infection
Secondary: urinary tract infection
Other: none

Common Presenting Problems/Findings with Specific Suggested Managements

PROBLEM | SUGGESTED DIAGNOSTIC STUDIES | THERAPEUTIC RECOMMENDATIONS
--- | --- | ---
Urinary symptoms | Urinalysis, urine culture | Antibiotics if indicated
Fever over 37°C | axillary temperature | Hand hygiene, review antibiotic regimen

MEDICATIONS:
- Proin 10mg os (2 tablets qd)
- Ceftazidime 1gm IV q8h
- Metronidazole 500mg q8h

VITALS:
- Temperature: 36.5°C
- Heart rate: 120 bpm
- Respiratory rate: 20 breaths/min
- Oxygen saturation: 98%

TECHNOLOGY SUPPORTS:
- Oxygen (5 L/min)
- Pulse oximetry
- Nasal cannula
- IV solution
- Monitoring

PATIENT CARE GOALS:
- Goal: None
- Date Set: None
- Target Date: None

COMPLEX CARE CONTACTS:
- Sherri Adams: Pediatric Medicine NP, pager: Sherri.Adams@sickkids.ca
- Dr. Eyal Cohen: Pediatric Medicine Pediatrician, phone: 416-813-7664 ext 20069
- Justin Perella: Complex Care Information Coordinator, phone: 416-813-7654 ext. 301197, pager: Justin.Perella@sickkids.ca
The following are process standards for the development, sharing, maintenance, and use of medical care plans:

1. Child/family enrolled in the complex care program have a medical care plan
2. Clinical key worker is responsible for the development and maintenance of the medical care plan in partnership with child/parent and care team
3. Child/parent approves the information included in the medical care plan
4. Parents coached and educated in the purpose and use of the medical care plans
5. Most up-to-date medical care plan is made available in the child’s medical record
6. The child/parent receives a copy of the medical care plan and works with the clinical key worker to identify the individuals/teams (hospital and community) required to receive the medical care plan
7. Medical care plans shared with identified care team (hospital and community) members and parent
8. Medical care plans reviewed and updated, as required, after each regularly scheduled complex care clinic visit, hospital admission, or as urgent changes arise
FAQs

What platforms are used to create the care plan?
Where does the care plan live?
How is it shared?

Who has access to it?
How is it used by the family?
How is it used by the care team?
Future Directions

- Sharing platforms
- Caregiver participation
Care maps are a pictorial way to assess and describe the individual needs, strengths and assets of a family and to provide a holistic view of the family experience.

- Created by Parents
- May be a tool to help families communicate “big picture” and “small details”
- Help HCP identify gap and prioritize care through the health care system
Navigating a complex system

The caregiving ecosystem for children and youth is more complex than for adults.
Abstract

Aim
Children with medical complexity require multiple providers and services to keep them well and at home. A care map is a patient/family-created diagram that pictorially maps out this complex web of services. This study explored what care maps mean for families and healthcare providers to inform potential for clinical use.

Method
Parents (n=15) created care maps (hand drawn n=10 and computer-generated n=5) and participated in semi-structured interviews about the process of developing care maps and their perceived impact. Healthcare providers (n=30) reviewed the parent-created care maps and participated in semi-structured interviews. Data were analysed for themes and emerging theory using a grounded theory analytical approach.

Results
Data analysis revealed 13 overarching themes that were further categorized into three domains: features (characteristics of care maps), functions (what care maps do), and emerging outcomes (benefits of care map use). These domains further informed a definition and a theoretical model of how care maps work.

Interpretation
Our findings suggest that care maps may be a way of supporting patient- and family-centred care by graphically identifying and integrating experiences of the family as well as priorities for moving forward.
FIGURE 2b
Co-Creation, Development and Evaluation of Online Care Maps for Children with Medical Complexity (CMC)

Sherri Adams (1,2,3), Blossom G. Dharmaraj (2), Madison Beatty (2), Clara Moore (2), Arti Desai (4), Leah Bartlett (5), Erin Culbert (6), Eyal Cohen (1,2,7), Jennifer Stinson (2,3,8), and Julia Orkin (1,2,7)

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AN ONLINE CARE MAP PROVIDED INSIGHT AND VALUE TO PARENTS AND CARE TEAM MEMBERS
Transition to Adult Care
Implications to inform policy and practice: Transitioning of YMC to Adult Care

Review

Lin Li*, Marissa Bird, Nancy Carter, Jenny Ploeg, Jan Willem Gorter and Patricia H. Strachan

Experiences of youth with medical complexity and their families during the transition to adulthood: a meta-ethnography

Transition to adult care for youth with medical complexity: Assessing needs and setting priorities for a health care improvement initiative

Lin Li, RN, BFA, BScN a, Anna Polanski, RN(EC), MN-NP (Paediatrics) a, Audrey Lim, MD, FRCPC, MSc b, Patricia H. Strachan, RN, PhD d
Transition to me equals sheer fear...It’s like jumping off a cliff. And if you’re really well prepared – you might have a parachute or a trampoline along the way for a short respite period there...

(Parent)
It was like after all those years we had depended on the (pediatric) hospital to help us, and now we had the impression that we were on our own. No one knew us, we were nothing. We were a number.

(Parent)
Content of the Transition Toolkit

Timeline

HCP Checklist

Youth & Caregiver Checklist

Transition Resource Guide
COMPLEX CARE FOR KIDS ONTARIO
Youth Transition to Adult Care Timeline

AGE 12:
- Obtain Social Insurance Number (SN), passport, birth certificate, Status card (if applicable)
- Set up bank account
- Apply for:
  - Assistance for Children with Severe Disabilities Program (ACSD)
  - Disability tax credit (DTC)
  - Registered disability saving plan (RDSP)
  - Accessible parking permits
  - Respite services
  - Review entertainment/recreational opportunities
  - Jordan's Principle
  - Inuit Child First Initiative (if applicable)

AGE 12-13:
- Identify/connect with adult primary care provider (PCP)
- For highschool – request copy of Individual Education Plan (IEP) & Identificaton, Placement and Review Committee (IPRC) meeting
- Request psychological assessment or letter if youth is untestable from psychologist

AGE 14:
- Review transition tasks with care team/family
- Discuss goals & priorities for future planning, including Goals of Care
- Confirm IEP completion
- Discuss healthy relationships/sexuality

AGE 15:
- Annual transition planning meeting with care team/family
- Begin Developmental Services Ontario (DSO) application to be submitted at age 16
- Learn about the adult care system
- Learn about Substitute Decision-Maker (SDM)

AGE 16:
- Continue annual transition planning meeting with care team/family
- Submit DSO application*
- Annual appointment (appt.) with PCP from here
- Discuss referral to adult specialists with all pediatric specialists
- Discuss legal guardianship
- Explore providers for dental & vision care

AGE 17:
- Periodic check-ins and final transition clinic meeting with care team/family
- Ensure appt. with all pediatric specialists to transfer care
- Overlapping/joint appt. with adult and pediatric specialists
- Develop a crisis plan of youth's daily routine
- Make a list of technology, equipment, supplies
- Submit Ontario Disability Support Program (ODSP) application at age 17.5*
- Transfer of home care services
- Determine future respite needs
- Request prescription refill for medications & enteral formula for 6 months
- Caregiver to have copies of care plan/key reports

AGE 18:
- Last check-in with paediatric team/family
- Adult care providers to have care plan/family consultaton note/relevant medical records
- Confirm 1st or 2nd appts, with PCP and all adult care specialists
- Receiving DSO and Passport funding, and ODSP after age 18

* = Time-sensitive tasks
This timeline presents some key tasks. Please see the full checklists and Transition Resource Guide for further details. Each age lists new tasks to do in addition to the items in the previous age as some tasks build on tasks listed in the preceding age.
Practical Tips: How can I use this Toolkit?

• The two Transition checklists are fillable – can be downloaded, saved and/or printed

• Inform families of the checklist as soon as you can and work in parallel with HCPs/Complex Care team based on age

• Use the checklist as a guidance and consider youth and family’s goals and expectations in the transition process

• Keep track of adult providers (PCP and adult specialists) as they are identified

• The bolded tasks are to be prioritized in the transition journey, putting deadlines is helpful to ensure tasks are not missed (prompting to set appt dates on caregiver’s phone)
References


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• https://www.pcmch.on.ca/wp-content/uploads/2022/05/CCKO-Youth-Transition-to-Adult-Care-Timeline_Final-Feb222022.pdf


Learning Objectives

- Describe challenges in care coordination for children with medical complexity (CMC) and their families
- Describe members of clinical team and role of key clinical worker
- Discuss the utility of care plans and care maps
- Review an approach to transition to adult care for CMC
THANK YOU