Manage Children with Medical Complexity in Your Practice

Dennis Kuo, MD, MHS, FAAP
Amy Houtrow, MD, PhD, MPH, FAAP

Thursday, December 15, 1-2 pm Central
American Academy of Pediatrics
Council on Children with Disabilities
DISCLOSURES

• We have no relevant financial relationships with the manufacturers(s) of any commercial products(s) and/or provider of commercial services discussed in this activity.

• We do not intend to discuss an unapproved/investigative use of a commercial product/device in this presentation.
FACULTY

Dennis Kuo, MD, MHS, FAAP
Associate Professor and Chief, General Pediatrics
Medical Director, Primary Care Services
Women and Children’s Hospital
University at Buffalo
The State University of New York
FACULTY

Amy J Houtrow, MD, PhD, MPH, FAAP
Chief, Division of Pediatric Rehabilitation Medicine
Vice Chair, Physical Medicine and Rehabilitation
Associate Professor, Physical Medicine and Rehabilitation and Pediatrics
Children’s Hospital of Pittsburgh
University of Pittsburgh School of Medicine
LEARNING OBJECTIVES

• Recognize medical complexity.
• Describe the role of the medical home model for children with medical complexity.
• Discuss strategies for providing care for children with medical complexity.
Recognition and Management of Medical Complexity

Children with medical complexity have extensive needs for health services, experience functional limitations, and are high resource utilizers. Addressing the needs of this population to achieve high-value health care requires optimizing care within the medical homes and medical neighborhood. Opportunities exist for health care providers, payers, and policy makers to develop strategies to enhance care delivery and to decrease costs. Important outcomes include decreasing unplanned hospital admissions, decreasing emergency department use, ensuring access to health services, limiting out-of-pocket expenses for families, and improving patient and family experiences, quality of life, and satisfaction with care. This report describes the population of children with medical complexity and provides strategies to enhance medical and health outcomes.

INTRODUCTION

Children with medical complexity (CMC), who may also be known as “complex chronic” or “medically complex,” have multiple significant chronic health problems that affect multiple organ systems and result in functional limitations, high health care need or utilization, and often the need for or use of medical technology.1,4 An example of a child with medical complexity is one with a genetic syndrome with an associated congenital heart defect, difficulty with swallowing, cerebral palsy, and a uterine condition. This child would typically require the care of a primary care physician, multiple pediatric medical subspecialists or pediatric surgical specialists, home nurses, and rehabilitative and habilitative therapeutic community-based services; extensive pharmaceutical therapies; special attention to his or her nutritional needs and growth; and durable medical equipment to maintain health, maximize development, and promote function.2

Children and youth with special health care needs (CYSHCN), who require health and related services for a chronic physical, developmental, behavioral, or emotional condition beyond what is typically required for children,3 have long been designated as a priority population of interest.
Why Children with Medical Complexity Matter

• Children with medical complexity (CMC) are increasing in number
• More CMC will be cared for in community settings
• CMC are a cornerstone of health care system reform
• CMC are at risk for health care inequities, poor health outcomes and limited participation in life events
**Definition: Children with Medical Complexity**

- Multiple significant chronic health problems
- Multiple organ systems
- Result in:
  - Functional limitations
  - High health care needs or utilization
  - Often require need for, or use of, medical technology
- Approximately 1% of children account for up to one third of overall health care spending
FIGURE 1
Definitional framework for CMC among other definitions of chronic conditions of childhood.\textsuperscript{29} In this framework, CMC are defined as children with characteristic patterns of needs, chronic conditions, functional limitations, and health care use. CCCs are as defined by Feudtner et al.\textsuperscript{24}
**Functional Limitations**

- CMC are impacted by their health condition(s) such that they cannot participate in activities that may be common for typically developing children.
- Disability may be permanent or temporary.
- Best understood using a model of disability that accounts for the changing nature of health, and the multiple inter-related impacts on functioning.
  - International Classification of Functioning, Disability and Health

<table>
<thead>
<tr>
<th>Impairments</th>
<th>Activity Limitations</th>
<th>Participation Restrictions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of the Body</td>
<td>Level of the Person</td>
<td>Level of the Person in Society</td>
</tr>
</tbody>
</table>
Health Condition  
(disorder or disease)

Body Functions & Structure  

Activities  

Participation  

Environmental Factors  

Personal Factors  

Contextual Factors

Adapted from: World Health Organization, 2007
**VIGNETTE**

- 12 year old with Rett’s Syndrome
- Recently relocated to metropolitan area to be closer to children’s hospital
  - Failure to thrive
  - Unhappy
- Three admissions for diarrhea and dehydration within four month period
- Missing school
- Single parent
- Family goal: gain weight
Recognizing Medical Complexity

- Conceptually: multi-organ system involvement
  - High prevalence of neurologic/neurodevelopmental disorders
  - May have underlying genetic disorder or prematurity
  - Technology dependence
- Consider context of social, community and functional issues
- No consensus yet on recognizing complexity at the population level
  - Diagnoses
  - High health care resource use
  - Need to predict who will require resources
- Health for CMC
  - Non-curative
  - Optimizing outcomes
IDENTIFYING CMC AT POPULATION LEVEL

• Methods used
  • ICD-9 and ICD-10 diagnosis and procedure codes
  • Algorithms examining codes associated with higher rates of specialty care, hospitalization, multi-organ involvement

• Existing tools
  • Complex Chronic Conditions (Feudtner)
  • Clinical Risk Groups (3M Health Systems)
  • Chronic Condition Indicator (AHRQ)
  • Pediatric Medical Complexity Algorithm (Seattle Children’s)
IDENTIFYING CMC ON INDIVIDUAL LEVEL

Can be subjective and may incorporate psychosocial drivers of health in addition to chronic conditions or health needs

Challenges for the provider:

- Time (“I don’t have time to address all of these issues”)
- Expertise (“I’m not familiar with this condition”)
- Financial challenges (“I won’t get paid for this”)

Often the patients who fall through the cracks

- “The specialist needs to handle this”
- “The primary care doctor needs to handle this”
THE IMPORTANCE OF PATIENT- AND FAMILY-CENTERED CARE

• Family understood to be child’s primary strength and support
• Foundation of care for CMC—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
  • Through trust, negotiation and mutual respect decisions are reached
• Importance
  • Outsized and unmet needs
  • Families understand health care system and the drivers for health
VIGNETTE

• 2 year old with Sickle Cell Disease (SCD)
• Traumatic brain injury (TBI) shortly after birth
• Went to foster care, then long-term care facility, then back to foster care
• Admitted repeatedly for fever and cough, concern for acute chest syndrome, but workup always negative
• Family goal: keep child out of the hospital
ASSESSING THE NEEDS OF CMC: THE TIP OF THE ICEBERG

• At first glance CMC require:
  • Primary care
  • Specialty care
  • Hospital care
• What else?
MEDICAL CARE IS A RELATIVELY SMALL PART OF DETERMINING HEALTH

Adapted From: Centers for Disease Control and Prevention, 2016
Care Map: What one child with medical complexity needs for optimal health

Reproduced with permission from Cristin Lind. Retrieved from: https://durgastoolbox.com/caremapping/
REAL-WORLD CHALLENGES FOR FAMILIES

- No gas money
- No transportation
- No permanent address
- Cell phone paid for monthly
- Limited health literacy
- Solo parent
- Multiple children with special needs

- Resources, therapies not available locally
- Primary care providers who may not be comfortable with management issues
**Family Experiences**

- “I feel like you guys have given me this devastating news that my child has a lifelong disability, and sent me afloat in an ocean and said, okay here it is, now go and do something about it....”
- “…No one has ever told me about what is available really. Other parents telling parents is where I get 99.9% of information.”
- “...We need stronger, more involved case management. We have a hotline for gambling and substance abuse, but nothing for those of us who deal with day to day (and sometimes minute to minute) airway problems.”
The Medical Home

- All CMC should have access to a medical home:
  - Continuous, comprehensive, coordinated, family-centered, compassionate, accessible, culturally effective

- Cornerstone of health care payment reform:
  - Expanded outpatient/primary care services

- Barriers include:
  - Lack of care coordination skills, training, payment, time, staffing, structural elements

- Health Neighborhood:
  - Coordinated between and within systems, cooperative with identified roles and expectations, communicative with delineation of goals
MOVING THE FIELD FORWARD – WHERE ARE WE NOW?

System of Care Quality Indicators for Children Who are Severely Affected

- Family Partnership and Satisfaction
- Care in a Medical Home
- Adequate Insurance
- Early and Continuous Screening
- Services Organized for Ease of Use
- Effective Transition Planning
- Total System of Care

Adapted from: Strickland, 2011
Tertiary Care Center-based Complex Care Services

- Dedicated complex care services
  - Multidisciplinary services
  - Specific expertise
- Some provide primary care, many are consultative
- Some act as medical home, others collaborate with primary care physicians
- Location at tertiary care centers confer a coordination advantage with specialty services but are often insufficient to meet needs of entire population of CMC
IDEAL MODEL OF CARE DELIVERY

• Medical home, rooted in community
• Family-provider-community partnerships
• Support primary care practices when desired
  • Continuity
  • Knowledge of child and family
  • Holistic approach to care
  • Community setting
PRACTICE ELEMENTS

• Registry of CMC

• Team-based approach:
  • Family caregiver
  • Designated staff care coordinator
  • Personal physician
  • Specialty care
  • Community-based supports: school, DME, pharmacy, therapies

• Defined roles for each, with designated key contact
PRACTICE ELEMENTS

• Identify CMC prospectively
• Scheduled periodic contact with medical home
• Tools
  • Care plans
  • Care templates
• Practice transformation elements
  • Quality improvement
  • Focus on CMC
Quality Improvement: Plan-Do-Study-Act (PDSA) Cycle

Plan
- What are trying to accomplish? Plan the initiative.

Do
- Implement the plan.

Study
- Evaluate the results.

Act
- Adapt the intervention if needed. Disseminate.
CARE PLANNING FOR CMC

- Goal? Develop Care Plans for CMC
- Decide which type of care plan
- Decide who will be in charge
- Decide how care plans will be implemented
- How will success be measured?
- Implement care plan development with a small number of CMC
- Incorporate care plans into medical record

- Revise for simplicity
- Integrate into workflow

- Evaluate the care planning process
- Determine family satisfaction
- Query if providers used it

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®
Payment Considerations: Fee-for-Service

- Psychosocial assessment and management, care plan development, non-face-to-face time necessary
- CMC care frequently not adequate reimbursed under FFS
- Compensation may require
  - Raising FFS payments
  - Compensation for non-face-to-face activities
  - Upfront payments
- Refer to coding resources
  - “Coding for Medical Home Visits”
  - “Coding for Telehealth Services”
Payment Considerations: Alternative Payment Models, Value-based Payment

- CMC are high resource utilizers and thus are target for health care reform
- Movement towards managed care models or fully capitated plans with assumption of risk
- Organization becomes responsible for totality of care
  - Unanswered questions include who is responsible, what is network, what are appropriate upfront payments and what is potential rate of return
  - Challenges include accurate identification of CMC, risk stratification, appropriate payment rates
SUMMARY: PEDIATRICIAN

- Identify CMC
- Provide team-based care with designated roles, including co-management with key specialty services
- Ensure key contact: care coordinator, designated medical home
- Utilize practice transformation tools, including registry, electronic care plan tools, communication among partners, quality improvement
- Recognize and advocate for community-based services
- Document and bill appropriately
SUMMARY: PAYER

• Adequate incentives for community-based providers
• Recognize value of non-face-to-face encounters and care management codes
• Consider integrated care systems and population-based payment models
**SUMMARY: POLICY**

- Distinct population of interest for clinical and research initiatives
- Education of residents, medical students, and continuing
- Adequate health insurance coverage and payment for preventive and necessary services
- Research examines identification of CMC, development and assessment of models of care, the impact value of CMC, and quality metrics
QUESTIONS
Optimal health, function, and development of children and youth with disabilities—in partnership with their families, providers, and communities—in all settings.

Visit the Council on Children with Disabilities Web site for more information.
REFERENCES


