Optimizing Care for Children with Medical Complexity

The 5th Annual ABC Conference
“Interprofessional Approach to Caring for Children with Special Needs”

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Disclosures

• No financial disclosures

• No discussion of off-label use of medication or medical technology

• Employed physician with Advocate Health Care and Advocate Medical Group
  – Advocate Children’s Hospital – Oak Lawn (ACH-OL)

• Board of Directors for the Ronald McDonald House Charities of Chicagoland and Northwest Indiana (RMHC-CNI)
Objectives

At the conclusion of this presentation, participants will be better able to:

• Distinguish Children with Medical Complexity as a unique population of Children with Special Healthcare Needs
• Identify factors and trends influencing the demographics of Children with Medical Complexity and their care
• Recognize the domains for identification and care implementation in enhancing care models for Children with Medical Complexity
• Identify opportunities for next steps in comprehensive care for Children with Medical Complexity and their families
Children with Medical Complexity

• Advances in medical and surgical technologies, particularly in Critical Care settings (NICU, PICU, and Surgical ICU’s) have significantly increased overall *survival* of children with previously fatal medical conditions
  • Infants *born prematurely*
  • Infants & children with congenital or acquired *chronic conditions*
  • Children who have suffered *major traumatic events*

• Many of these patients go on to become *Children with Special Health Care Needs (CSHCN)*
  • Those CSHCN with the most intensive health care need are referred to as *Children with Medical Complexity (CMC)*
Definitions of CSHCN

• American Academy of Pediatrics (AAP) Policy Statement
  • “[children] who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”

• Agency for Healthcare Research and Quality (AHRQ) definition
  • Children who have 2 or more active chronic conditions

• Identified via various survey and administrative data sets
  • National Survey of Children with Special Health Care Needs (NS-CSHCN)
    – Illustrate the social, emotional and societal impact of CMC
  • Numerous ICD9 filters identifying Neurological Impairment (NI) and Technology Assistance (TA)
    – Strong face validity, but may underestimate overall complexity both medically and societally
Children with Medical Complexity

• Generally accepted cardinal domains for CMC
  – Chronic, severe health conditions
  – Substantial health service needs
  – Functional limitations which are often severe
  – High health resource utilization

• Ideal approaches for *identification* of CMC accounts and attempts to address all four domains
# CMC Stratification by 3M Clinical Risk Groups (ICD9 filter)

<table>
<thead>
<tr>
<th>ACUTE</th>
<th>CHRONIC</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CRG 1</strong></td>
<td><strong>CRG 2</strong></td>
</tr>
<tr>
<td><strong>Acute</strong></td>
<td><strong>Significant acute</strong></td>
</tr>
<tr>
<td>Minor chronic in 1 body system</td>
<td>Multiple minor chronic in 2 or more body systems</td>
</tr>
</tbody>
</table>
Children with Medical Complexity

• The US prevalence of CMC has **tripled** over the past 20 years
  – Now account for 4-18% of all US children
  – Approximately 3-11 million children

• CMC disproportionately utilize hospital resources
  – Rate of **hospital usage doubled** for CMC in past 20 years
  – CMC consume more than 25% of all pediatric hospital days and 40-70% of pediatric hospital charges
    • Largely due to their specialty or **tertiary care service needs**
      – Neurologic impairment – 57%
    • and **technology dependence**
      – Gastrostomy tube – 56%
Multiple Chronic Conditions and Technology Dependence

Pediatric Patients With Two or More Complex Chronic Conditions 2003 vs. 2009

- 2003: 5.6%
- 2009: 7.7%

Pediatric Patients with Technology Dependencies 2003 vs. 2009

- 2003: 10.9%
- 2009: 13.0%

Source: 2003-2009 PHIS data; excludes 18 and older; OB and normal newborns, hospitals added after 2003.
Health Care Utilization

• Pediatric specialty or tertiary services are difficult for hospitals to acquire and costly to maintain
• Nationally, non-newborn pediatric admissions account for only 5% of all hospital admissions
• Given small comparative volume and high comparative costs, coupled with expected increased adult service needs
  – trend is for smaller or community Pediatric hospital facilities to reduce or close services
  – trend of pediatric admissions to larger, historically, teaching children’s hospitals
Health Care Utilization

Medically Complex Children Enrolled in Medicaid, 2012 Discharges, Children’s Hospitals

Data Source: Children’s Hospital Association Case Mix Comparative Database Program
Tertiary Childrens’ Hospital Admissions

### Percent of Admissions With A Complex Chronic Condition

![Bar Chart]

- **Children's**: 36%
- **Non-children's**: 19%

Patients seen in a Children's hospital are **twice as likely** to have a complex chronic condition.

### Percent of Admissions With A Technology Dependency

![Bar Chart]

- **Children's**: 11%
- **Non-children's**: 4%

Patients seen in a Children's hospital are **nearly three times as likely** to have a tech dependency.

**Source:** 2006 KID data; excludes 18 and older; OB and normal newborns.
Health Care Utilization

• In general, CMC are visiting hospitals more often, but for shorter durations
  – Advances in minimally invasive surgical (laparoscopic) and peri-surgical (endoscopic and interventional radiologic) procedures have lead to faster recovery
  – Advances and availability of home care technology, assisted living and rehabilitation services leads to earlier discharge out of hospital settings
  – Mean LOS of 12 days
Health Care Utilization

• Effectiveness of utilization
  – Hospital 30-day readmission rates for CMC increase with complexity
    • 5.4% for CMC with one chronic condition
    • 9.4% with two chronic conditions
    • 12.4% with three
    • 16.8% with four or more
  – Families cite dissatisfaction with resolution of admitted concern and lack of understanding of how to manage their child’s needs at home as common reasons for readmission
Health Care Utilization

• Preventable readmissions
  – Current percentage, unknown
  – Ambulatory Care Sensitive Conditions (ACSC’s)
    • Asthma is the most common
    • Pneumonia and seizures
    • Medication errors
  – Technology malfunctions
    • Minimized with proper surveillance
      – Gastrostomy tubes, tracheotomy tubes, CSF shunts
      – Feeding pumps, medication pumps, oxygen and nebulized medication delivery systems
      – Operator error
Children with Medical Complexity

• Generally accepted cardinal domains for CMC
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• Ideal approaches for caring for CMC accounts and attempts to address all four domains
Caring for Children with Medical Complexity

• **Patient/Family Centered Medical Home (PCMH)** is particularly suited to caring for medically complex children (and adults)

• AAP Policy Statement defines a medical home as “accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective to all children and youth, including children and youth with special health care needs” (Desch, “The Seven C’s”, 1987)
Caring for Children with Medical Complexity

• Accessible care
  – CMC have a high likelihood of acute compromise
    • Acute illness, technology failure
    • Delay in care may lead to rapid and dramatic decline
  – Even when care is available, it is often difficult to deliver
    • Differentiating acute versus chronic illness
    • Availability and accuracy/completeness of records
    • Myriad of Subspecialists to contact
Caring for Children with Medical Complexity

• Coordinated care
  – Multiple complexities affecting multiple organ systems
    • Poly-pharmacy, medication errors
    • “Collusion of Anonymity”
      – Assumptions that other care providers or specialists are addressing certain concerns
  – Ideally care coordination is performed with family and each member of the care team
    • All of the CMC’s conditions and all of those affected by the decisions made, advocate for best outcomes
Caring for Children with Medical Complexity

• Comprehensive care
  – At least one care provider must provide a big-picture approach
    • Assess each need in the context of the CMC’s and family’s overall health
  – Allows for the prioritization of needs and the potential for discovering unmet needs
    • Anticipate and proactively address potential concerns
    • Avoid crisis-driven care
      – More often excessive, emergent and hospital-based
Caring for Children with Medical Complexity

• A tall task with no established “ideal” solution
  – Enhance Primary Care support
    • Dedicated personnel
    • Extended visits
    • Accessible medical records
      – Portable Family Care Summary
    • Quality Measures
  – Dedicated CMC outpatient programs
    • Primary Care vs. Consultation/Co-management Care
  – Dedicated CMC inpatient programs
    • CMC are known to utilize many hospital resources, need to coordinate care and improve transitions of care
  – Integrate community care resources
    • Home and school nursing, therapy services, home health vendors
Caring for Children with Medical Complexity - Enhance Primary Care

• Dedicated Personnel within the PCMH
  – Nurse Practitioners, Nurse Champions, Care Managers
  – Coordinate care between care team and community

• Extended office visits
  – 1.5-2x duration of routine HMV’s (30-60min)
  – Modified systems approach

<table>
<thead>
<tr>
<th>Home/School</th>
<th>Feeding &amp; Nutrition</th>
<th>GI</th>
<th>Respiratory/ENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>CV</td>
<td>Neurologic</td>
<td>Renal</td>
<td>Orthopedic</td>
</tr>
<tr>
<td>Hematology</td>
<td>Endocrine</td>
<td>ID</td>
<td>Transitions</td>
</tr>
</tbody>
</table>

– Extend access for urgent care in the ambulatory setting
Caring for Children with Medical Complexity - Enhance Primary Care

• Portable Family Care Summary
  – Empowers patients and families in care decisions
  – Increases access to health records
    • Helps differentiate chronic from acute conditions or changes
    • Increases likelihood for medication and technology reconciliations
    • Promotes communication and coordination with multitude of care providers and community resources

• Health Information Exchanges
  – Mobilization of healthcare information electronically across organizations within a region, community or hospital system
Caring for Children with Medical Complexity - Enhance Primary Care

• Measurement
  – Gaps exists in assessment of quality of care delivered
  – Expert panel examined evidence for primary care based on the patient-centered medical home model
    • Intent was to identify valid and meaningful quality measures for use in complex pediatric patients
  – Final set of quality measures:
    • Primary care–general (14)
    • Patient/family-centered care (8)
    • Chronic care (2)
    • Coordination of care (9)
    • Transition of care (2)
<table>
<thead>
<tr>
<th>Measure No.</th>
<th>Measure Text</th>
<th>LOE</th>
<th>Content Type</th>
<th>Data Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 (N)</td>
<td>The primary care team should work with the patient's family to specifically develop a management plan that includes visit schedules and communication strategies.</td>
<td>IV</td>
<td>Process</td>
<td>Chart</td>
</tr>
<tr>
<td>2 (N)</td>
<td>The primary care team should document counseling about nutrition when a child's BMI is ≥85 percentile for age and gender or note a reason for not doing so.</td>
<td>III</td>
<td>Process</td>
<td>Chart</td>
</tr>
<tr>
<td>Coordination of care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 (N)</td>
<td>The primary care team or the medical home should track laboratory tests and referrals to subspecialists.</td>
<td>V</td>
<td>Process</td>
<td>Practice-based survey</td>
</tr>
<tr>
<td>2 (P)</td>
<td>The primary care team should give timely referral to patients: “In the last 12 months, when your child needed a referral to a specialist, how often were you able to get the referral from your child's primary care provider?”</td>
<td>IV</td>
<td>Process</td>
<td>Patient survey</td>
</tr>
<tr>
<td>3 (P)</td>
<td>The primary care team should help patient/parent(s) coordinate care: “In the last 12 months, how often did you get as much help as you wanted with arranging or coordinating your child’s care?”</td>
<td>V</td>
<td>Process</td>
<td>Patient survey</td>
</tr>
<tr>
<td>4 (N)</td>
<td>The clinic or medical home should have a designated person responsible for care coordination.</td>
<td>IV</td>
<td>Structure</td>
<td>Practice-based survey</td>
</tr>
<tr>
<td>5 (P)</td>
<td>The primary care team should follow-up with parents on visits to specialists: “How often did your child's primary care provider or staff talk with you about what happens during visits to a specialist doctor?”</td>
<td>III</td>
<td>Process</td>
<td>Patient survey</td>
</tr>
<tr>
<td>6 (N)</td>
<td>At every visit, the primary care team should have the patient's medical record available.</td>
<td>IV</td>
<td>Process</td>
<td>Practice-based survey</td>
</tr>
<tr>
<td>7 (N)</td>
<td>The clinic should maintain a list (updated yearly) of children with special or complex health care needs with diagnoses.</td>
<td>IV</td>
<td>Process</td>
<td>Practice-based survey</td>
</tr>
<tr>
<td>8 (N)</td>
<td>The primary care team should clearly and specifically document if a patient has special or complex health care needs.</td>
<td>IV</td>
<td>Process</td>
<td>Chart</td>
</tr>
<tr>
<td>9 (N)</td>
<td>The primary care team should document in the chart about community-based services that the child and family use.</td>
<td>V</td>
<td>Process</td>
<td>Chart</td>
</tr>
</tbody>
</table>
Caring for Children with Medical Complexity - Enhance Primary Care

- Enhanced Primary Care as well as Dedicate CMC outpatient programs and Dedicated CMC inpatient programs have shown measurable clinical improvements
  - Care Plan utilization, care coordination rates, preventing emergency room visits, preventing hospital readmissions, decreased caregiver time missed from work
- Cost savings to hospitals have also been shown
- Overall cost savings are neutral or even negative
  - Cost of personnel, care coordination, lengthy office visits
  - Fee-for-service arrangements not conducive to profitability of these outpatient care models
Impact on Families

• However, despite medical advances, the prevalence of CMC in the US drops precipitously to approximately 6% of all children 5yo – 15yo in the US
  – Underscores the very difficult processes both CMC and their families endure, particularly in the first decade of life.

• The parents of CMC report higher rates of psychological stress and chronic back pain, as well as lower rates of sleep and community involvement.

• The siblings of CMC report similar rates of increased stress and overall lower participation in extracurricular activities, as well as less time spent with parents
Impact on Families

• Opportunities for Improvement
  – Some programs have demonstrated improvement in meeting the physical demands of families caring for CMC
  – Despite even the most rigorous implementation of dedicated CMC outpatient programs little effect has been demonstrated on meeting the emotional needs of families
  – Implantation of more comprehensive transition programs and links with community-based respite and behavioral health services may hold promise
Conclusions

• CMC’s are unique in their:
  – Chronic, severe health conditions
  – Substantial health service needs
  – Functional limitations which are often severe
  – High health resource utilization

• Recognizing and strategizing around these domains in identifying and creating care models for CMC is needed

• Patient Centered Medical Home is particularly suited to caring for CMC
  – Accessible, coordinated and comprehensive

• Opportunities still exist in improving measureable outcomes for CMC and their families
References

• Murphy, et al. “Parent-Provider-Community Partnerships: Optimizing Outcomes for Children With Disabilities.” *PEDIATRICS.* Vol. 128, No. 4, October 2011. (L. Desch, MD contributed to this report.)
Acknowledgements

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Thank you.

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