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The Landscape of Medical Care for Children with Medical Complexity

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ABSTRACT

Children with medical complexity (CMC) are an important group of children who have multifaceted clinical and functional needs that can be challenging to manage and treat in the current health care system. Although there is no standard definition of medical complexity, four cardinal domains characterize CMC: 1) chronic, severe health conditions; 2) substantial health service needs; 3) major functional limitations; and 4) high health resource utilization. CMC likely represent less than 1% of all children, yet they account for over one-third of pediatric health care costs. Inpatient care is responsible for as much as 80% of health care cost for CMC and use of the hospital is increasing for CMC over time. It is hypothesized that some inpatient utilization for CMC could be avoided with better ambulatory care.

Care for many CMC is currently fragmented, uncoordinated, and crisis-driven with a tendency to over-medicalize the child and to under-support the child's family caregivers. Several single-centered, quality

improvement studies of outpatient care for CMC report a reduction in inpatient utilization. However, most of these studies have designs that can neither determine causality nor quantify the true amount of cost savings attributable to improved quality of care. Although best practices have not been identified, the ideal model of care for CMC is suspected to be one that: 1) provides urgent care in the outpatient setting to treat acute health problems; 2) contains at least one outpatient provider who comprehensively addresses acute and chronic medical, functional and psychosocial needs; 3) coordinates decision making among all participating health care providers; and 4) develops effective, proactive plans of care to maximize the child's well-being and proactively anticipates health problems that are likely to occur. Because much of this type of care is not necessarily delivered during face-to-face health care encounters with CMC, it is poorly reimbursed in most fee-for-service payment models. Health system redesign is necessary to improve the ecology of care for CMC and their families.

INTRODUCTION

Children with medical complexity (CMC) represent an important group of children who have clinical needs that are often challenging to address in our current health care systems. This growing population of children with high levels of health care needs, utilization, and cost has a substantial impact on the pediatric health care system. Care for CMC is less than ideal. It is often fragmented and uncoordinated across community, outpatient, and inpatient providers with inadequate communication and proactive care planning. There is ample opportunity to improve the health and health care for these children and their families.

Current health care systems are poorly designed to provide high quality of care for CMC and their families. There are few incentives for providers to take ownership of CMC, to make sure that the children's needs are met in a timely fashion, or to take the time to plan for health problems that are likely to occur in the future. Recent developments in health care reform have generated interest in aligning CMC with an integrated model of care across the care continuum that will be designed to better meet their needs and optimize their health. Such reform would likely decrease duplications and gaps in care, leading to improved outcomes and lower health care costs.

Effective reformation of health care for CMC requires 1) clear definitions of who CMC are, and what are their core health care needs; 2) identification of what evidence-based care processes have the greatest impact on their health and functional outcomes; and 3) determination of what amount of cost savings, if any, might be achievable with improved health care delivery. Therefore, we drew upon the existing literature as well as ongoing research and quality improvement projects to describe the current understanding of these issues in this report. We also took the liberty, where appropriate, to include our own experiences with and perceptions of these issues.

This report contains four sections. The first section reviews current algorithms used to define CMC and discusses ways to identify CMC who are likely to benefit the most from an integrated health care system. The second section describes the attributes of an ideal model of outpatient, inpatient, and community-based care for CMC. The third section describes the utilization and cost of CMC as well as the evidence of potential savings that might be achieved with improved quality of care. The last section provides suggestions for urgently needed ongoing research and reform.

PART I

Definitions of Children with Medical Complexity

Medical complexity is subjective; recognition of it varies by the experiences, perceptions, and beliefs of those trying to assess it. CMC are inherently heterogeneous with a spectrum of conditions, needs, limitations, and medical fragility. As a result, it is not easy to identify them as a group.

Although there is no standard definition of medical complexity, four cardinal domains characterize CMC:¹

1. Chronic, severe health conditions
2. Substantial health service needs
3. Functional limitations which are often severe
4. High health resource utilization

Here is an example of a child with medical complexity who possesses all four of these domains:

A 9-year-old child with spina bifida and eight different co-morbid conditions (domain 1); who relies on the care of 17 different health care providers and allied health professionals (domain 2); who is dependent on a wheelchair for mobility and a gastrostomy tube for nutrition (domain 3); and is routinely hospitalized five to ten times per year (domain 4).

There is ongoing discussion in the context of health system reform about whether CMC are a distinct population of children that should be considered, conceptually, separate from children with special health care needs (CSHCN). Proponents for a distinct CMC population argue that CMC have such intensive health care needs that even systems that may be well-designed to care for most CSHCN may be inadequate for CMC.

Identifying Children with Medical Complexity

There are several approaches to identify CMC among all pediatric populations. It is important to recognize that each identification method may produce unique results (e.g., total number of patients, health conditions, and health resource impact) with varying degrees of sensitivity and specificity against a gold standard for identifying CMC (i.e., clinical assessment with chart review, patient interview and physical examination).

Diverse stakeholders may have different needs and objectives for identifying CMC. Stakeholders affiliated with a clinical program for CMC that has limited clinical personnel and resources may wish to identify CMC with needs that are inadequately met by traditional primary and subspecialty care structures; these clinical stakeholders

might favor a more precise (i.e., strict) approach for CMC identification with a higher threshold for program enrollment. Alternatively, research and policy stakeholders may benefit from less precise (i.e., less restrictive) methods of CMC identification when attempting to describe the clinical and economic impact of CMC throughout a state, region, or country; and when attempting to screen CMC for enrollment into system-level initiatives to improve care.

These types of data have been used to identify CMC:

1. Survey data
2. Administrative data with diagnosis and procedure information
3. Health care utilization data

Survey Data

Existing pediatric survey questionnaires are available that assess a child's diagnoses, health service needs, functional status, and health care utilization. These surveys are administered to patients' families and health care providers. The best example of such a survey is the National Survey of Children with Special Health Care Needs (NS-CSHCN).^{2,3}

The NS-CSHCN, administered through a telephone survey, asks parents whether their child had a chronic condition lasting at least 12 months that resulted in any of the following:

1. Need for prescription medications
2. Need for more medical care than usual
3. Limited ability to do things
4. Need for occupational, physical, or speech therapy
5. Presence of emotional or behavioral problems

Many CMC have substantial unmet needs for certain health services such as therapies, outpatient specialty care, durable medical equipment, and home care. The family caregivers of CMC also have needs (e.g., respite care, family leave from work, etc.) that, if not met, can lead to caregiver burnout and ill health of both the family and child.⁴ Although the NS-CSHCN does not collect information on all of these needs, it has been used to identify complex sub-populations of CSHCN using the following two-part definition:²

1. Positive response to the item on the CSHCN screener indicating "need for more medical care" than usual
2. Positive responses to at least three of four remaining items on the CSHCN screener

Other survey instruments focus on one domain of CMC (e.g., activities of daily living/functional ability).⁵⁻⁸ One

example is the Gross Motor Function Classification System (GMFCS), which is used to stratify the severity of disability in children with cerebral palsy into five categories with good prognostication.⁹ The GMFCS has also been used to categorize the severity of disability in other chronic conditions (e.g., Down syndrome).¹⁰ Although very useful to assess one particular domain, instruments like the GMFCS are not equipped to identify CMC without the benefit of additional information of the other CMC domains.

There are strengths and weaknesses when using a survey to identify CMC. Survey strengths are: 1) they provide information on health service needs and functional abilities that are not currently available in standard administrative datasets; and 2) they provide important information of complexity from the patient, family, and clinician perspectives. In adults, this information has been beneficial when identifying patients with medical complexity in a population and predicting health outcomes and health care expenditures. One limitation of using survey data to identify CMC is that the data collection is labor intensive and expensive to implement. Moreover, although suspected to be very valuable, using a survey to prospectively identify CMC for clinical purposes has not been validated or tested for reliability against a gold standard (e.g., chart review or patient interview). The NS-CSHCN has been primarily administered in telephone surveys and its utility in the practice setting has yet to be established.

Administrative Data with Diagnosis and Procedure Information

International Classification of Diseases (ICD) diagnosis and procedure codes have been used to identify CMC who have characteristic chronic and severe health conditions (domain 1) and functional limitations (domain 2). Several approaches using ICD codes to identify CMC are described below.

1. **Feudtner's Complex Chronic Conditions (CCC)** include childhood health conditions that are expected to last longer than 1 year and that are associated with high morbidity and mortality as well as high resource utilization. There are nine categories of CCCs (based on organ systems) and 31 subcategories; children with CCCs in more than one organ system tend to have more complex needs.¹¹ The CCCs are defined with ICD9^{12,13} or ICD10¹⁴ diagnosis codes. The vast majority of children who utilize a structured clinical program for children with medical complexity have one or more CCC diagnosis codes. However, it is important to understand that the CMC enrolled in complex care programs may not be representative of CMC populations throughout the pediatric health

care system. Programs for CMC tend to have a high prevalence of children who have severe neurological impairment and a low prevalence of CMC who have hematologic/ oncologic or chronic kidney problems. Many other CMC are cared for by specific pediatric subspecialty programs in children's hospitals (i.e., liver transplant program).

2. **3M Clinical Risk Groups (CRGs)** rely on utilization data and ICD-9 codes to classify individuals into hierarchical groups of increasing complexity and severity.¹⁵⁻¹⁷ Each patient is classified into one of nine core health status groups. The groups range from healthy children without a chronic condition to unhealthy children with a catastrophic chronic condition associated with high morbidity and mortality. The CRGs can assess whether a child has a single or multiple chronic conditions. CMC have been identified with CRG groups 6, 7, and 9, which (as a group) represent children with significant chronic conditions affecting two or more body systems and/or a complex or progressive chronic condition.¹⁸ CRG group 5, in general, represents children with a single, lifelong chronic condition that affects only one body system.
3. **Chronic Condition Indicators (CCI)** are a classification system developed by the Agency for Healthcare Research and Quality (AHRQ)¹⁹⁻²² to dichotomize ~14,000 ICD-9 diagnosis codes into chronic or non-chronic conditions, and to aggregate each chronic condition into 1 of 18 mutually exclusive clinical groups. Unlike the CCCs and the CRGs, the CCIs are not specific to children. However, they have been used to count the number of chronic conditions that a child endures as an indicator of medical complexity.^{1,22} The higher the number of chronic conditions, the higher the utilization of health resources.²²
4. **Neurological Impairment (NI)** comprises a heterogeneous group of static and progressive health conditions that involve the central and peripheral nervous systems and result in functional and/or intellectual impairment. This group includes children with epilepsy, infants who are born prematurely and have hypoxic-ischemic injury to the brain, and children with genetic and metabolic disorders that affect the nervous system. Children with severe NI tend to have multiple secondary chronic diseases (i.e., co-morbid conditions) that affect other areas of their body (e.g., digestive, lung, musculoskeletal) and they frequently rely on medical technology (e.g., feeding and breathing tubes) to maintain their health. CMC who utilize structured clinical programs for complex

care have a very high prevalence of NI. A list of 606 ICD-9 diagnosis codes that indicate NI has been validated through a modified Delphi process and used in several studies to describe CMC and their health resource utilization.²³

5. **Technology Assistance (TA)**; children assisted with technology are those who rely on a medical device to manage and treat a chronic illness (e.g., a ventricular shunt to treat hydrocephalus), to maintain basic body functions necessary for sustaining life (e.g., a tracheostomy tube for breathing), or to maintain/improve overall functional status (e.g., a wheelchair to improve mobility and other activities of daily living). Congress' Office for Technology Assessment created a working definition for the technology assisted child as one who "needs a medical device for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability."²⁴ This definition was adapted by Feudtner to: "if the technology was to fail, or use be discontinued, [the child would] likely suffer a sufficiently adverse health consequence [that required hospital care to treat]."²⁵ No expert panel or other validation process has determined which technologies should be included in the TA definition. There is major variation in the complexity and fragility of children who use a technology (e.g., many children who use a wheelchair are not medically complex or fragile). TA that is associated with a medical procedure (e.g., tracheostomy of gastrostomy tube) is much easier to capture using administrative databases than TA that is not (e.g., use of a wheelchair). Despite these caveats, TA has been used to identify CMC and the presence of TA correlates strongly with increased health resource utilization.
6. **A new approach for CMC identification is being developed** and validated at Seattle Children's Research Institute.²⁶ Preliminary presentations from the developers suggest that the approach uses ICD-9 diagnosis codes to categorize children into three mutually exclusive groups: 1) children without a chronic condition, 2) children with a non-complex chronic condition, and 3) children with a complex chronic condition.

There are several strengths and weaknesses of using administrative data to identify CMC. The strengths are: 1) ICD-9 codes have strong face validity; that is, most of the diagnosis and procedure codes are characteristic of the clinical gestalt of a CMC; and 2) the ICD-9 codes are included in most hospital, state, and federal administrative claims datasets. The weaknesses are: 1) additional work is needed to validate the use of these ICD-9 codes against a

gold standard; 2) for inpatient claims data, ICD-9 codes are entered by administrative billing personnel rather than clinicians; 3) there is variation in the specific codes used for the same health condition across institutions and over time;²⁷ 4) CMC are at risk for being under-coded (i.e., some of their health conditions are not entered as ICD-9 codes for billing purposes) because the conditions do not increase the amount of reimbursement or the child has not had the condition long enough for it to be recognized as a chronic condition; and 5) ICD-9 diagnosis codes, when used alone, may underestimate complexity and needs of many children, particularly those with neurodevelopmental conditions.²⁸

Prevalence of Children with Medical Complexity by Definition Approach

The survey and administrative data approaches that have been used to identify CMC produce similar estimates of prevalence. On a population level, CMC account for 0.4% (CRG data (groups 7 and 9) from a health plan in Washington state from 1999)²⁹ to 0.7% (children with one or more CCCs or neurologic impairment in Ontario, Canada)¹¹ of all children. Prevalence of CMC may be higher in certain sub-populations of children (e.g., children with Medicaid) that are prone to have a higher rate of chronic conditions and disability.

Conclusions for Definitions of CMC

Although consensus has not been reached on which definition or which approach best identifies CMC, all of the currently used approaches have good face validity and, on the surface, they all seem to work relatively well. The ideal approach should be one that captures all four domains of medical complexity (i.e., chronic, severe health conditions; substantial health service needs; functional limitations; and high health resource utilization). We believe that children with all four of these attributes are the ones who are highly likely to benefit the most from care coordination and system redesign.

Regardless of the intended use (i.e., clinical care delivery, risk adjustment, policy, etc.) a definitional approach for CMC that utilizes both survey and administrative data is likely needed because administrative data may not be equipped to capture accurate information on health care needs or functional status, and survey data may not be able to feasibly capture detailed information on diagnostic data or health care utilization. Using only one type of data will likely be imprecise, capturing a noisy

(continued)

population with substantial variability both in complexity and in the opportunity for quality improvement and cost savings.

Part II

Clinical Care Delivery for Children with Medical Complexity

Ideally, best practices for delivering clinical care to CMC should address the domains characterizing these children. That is, care should:

1. Mitigate the severity of the child's chronic health conditions
2. Effectively meet the needs of the child and family in a timely manner
3. Maximize the child's functional abilities
4. Minimize avoidable hospitalizations as well as other ineffective and/or unnecessary use of health resources

It is believed the ideal model of effective clinical care for CMC is encapsulated by the medical home concept of the American Academy of Pediatrics (AAP). First described in 1967,³⁰ the medical home, in concept, is a flagship site of care; it is a "go-to" place where the child can get, theoretically, all of the care that they need. The medical home has evolved to represent care that is *accessible, continuous, comprehensive, coordinated, compassionate, culturally competent, and family-centered*.^{31,32} Although valid and meaningful in theory, operationalizing these care attributes into discrete, effective care processes that can be implemented and measured has been challenging to apply to CMC.

Although most evaluations of the medical home are lacking a strong study design, the preponderance of evidence reports a positive relationship between the medical home and better health status, timeliness of care, family centeredness, and improved family functioning for CSHCN.³³ Three medical home attributes that we believe are particularly important for CMC – accessible, coordinated, and comprehensive care – are discussed in more detail below.

Accessible Care

Many CMC have a high likelihood of experiencing problems (e.g., acute illnesses, technology malfunction, etc.) that, if not addressed in a timely manner, may lead to a rapid decline in their health. It is very important, then, that CMC have access to an outpatient clinical site that

can urgently address their health care needs in person or over the phone. It is hypothesized that the absence of such a site contributes to increased emergency department visits, hospitalizations, and readmissions. Providing accessible urgent care for CMC is often not easy or quick. It can sometimes take hours to sort through an acute health problem in one of these children (e.g., imagine a three hour outpatient work-up for increased somnolence in a child with cerebral palsy; the work-up includes two phone calls to specialists, laboratory and radiographic testing, and a lengthy period of observation).

Coordinated Care

Many CMC have chronic conditions that affect multiple organ systems of their body. As a result, the children rely on multiple specialty pediatricians to, independently, treat each system. Because body systems, by design, are integrated with each other, instituting a care plan to treat one body system may adversely impact another system. For example, a gastroenterologist may start the medication erythromycin for improved bowel motility in a child with seizures without recognizing the medication may increase the child's seizure frequency. It is critical for medical decisions to be coordinated among the members of a child's health care team to ensure that appropriate plans of care are designed and executed. Care coordination in this situation implies that care planning decisions are communicated and actively discussed with the family and member of the child's care team within the context of all the child's health problems and issues.³⁴ This is not a simple task, especially when the child has several different clinical providers and when there is discordance among team members about a particular medical decision.

Comprehensive Care

Because CMC tend to have multiple health problems and needs that interact with each other, it is very important for at least one health care provider to approach the child comprehensively; that is, the provider systematically assesses each problem and need in the context of the child's overall health and well-being. The type of provider (e.g., physician, nurse, case manager) performing these assessments varies by program and practice. This comprehensive assessment is necessary to develop overarching goals of health and to create complete, proactive plans of care designed to keep the child as healthy as possible. In our experience, this assessment often identifies unmet needs and neglected health problems that require attention. Once extensive knowledge of a CMC is gained by the comprehensive provider, future health problems are more likely to be anticipated, planned for, and addressed. Without plans of care that proactively address what should be done for a child when they

encounter a future problem, CMC will continue to experience crisis-driven management. When this happens, the child may be more likely to be over-treated and more likely to require emergency and hospital care.

In the existing health care system, many CMC do not receive all of these attributes of care. Several reasons for this are described below:

- The foundation of the medical home lies in pediatric primary care, where the strongest links to community-based supports and services likely exist. However, many primary care physicians in the community do not feel equipped to provide high quality care to CMC because the conditions CMC endure are complicated. Many of the health needs of CMC lie outside the scope of primary care, and too much time is needed to undertake a comprehensive assessment, develop proactive care plans, and offer urgent care to treat acute health problems.³⁵⁻³⁷
- It is common for CMC to have as many as 10 or 20 different health providers and allied health professionals involved in their care.³⁸ Coordinating care among these health providers is very difficult to do out of a community-based, primary care practice or any single subspecialty practice. Often, the roles and responsibilities of the members of a child's health care team are ill defined. In addition, vital health information of CMC (e.g., medications, equipment, and problem lists) can be disorganized, obsolete, and largely inaccessible. Sometimes, primary care providers, as well as parents and other care team members, incorrectly assume the comprehensive needs of a CMC are being addressed by someone else. As a result, omissions and other errors in care can occur.

Several strategies have emerged to overcome these issues and to improve the quality of care for CMC.

- **Enhance existing primary care practices through dedicated personnel** (e.g., nurse practitioners, case managers, social workers, parent advisors) to assist CMC; implementing tools to assist with care planning (e.g., paper or electronic-based "medical passports"); and offering extended visits (e.g., 30 or 60 minutes) for needs assessments, care planning, and urgent visits.^{39,40}
- **Develop outpatient clinical programs dedicated to serving CMC.** Some programs provide primary care to enrolled patients⁴¹ whereas other programs provide consultative or co-management care to children who retain their relationships with their primary care physician.⁴² Some programs are highly

specialized (e.g., a clinic for cardiac transplant patients) whereas others are loosely defined (e.g., a clinic for children who have a chronic condition that affects three or more body systems). Some are multi-disciplinary (e.g., a cerebral palsy clinic staffed with a developmental pediatrician, orthopedic surgeon, physiatrist, and neurologist) whereas others are not. There is tremendous diversity to the structure of complex care programs driven by local needs, resources, and other considerations, but most programs offer the ability to perform a comprehensive health care needs assessment and to develop plans to fulfill unmet needs.

- **Develop inpatient services dedicated to serving CMC.** CMC are frequently hospitalized for an acute illness, a chronic illness exacerbation, or a major operation or procedure intended to improve their health.⁴³⁻⁴⁵ During these admissions, complex care hospitalists, nurse practitioners, social workers, and case managers may help oversee the goals of and plans for the admission; initiate and sustain the dialogue among the child, their family, and care team members; reconcile important health information (e.g., medications); and help with transitions of care including hand-offs within the hospital as well as transitions from the hospital to home.^{46,47}
- **Integrate community care for CMC.** CMC often require community-based services, in addition to outpatient and hospital services, to optimize their health, functioning, and well-being. Examples of community-based services include community case management and social work, home and school nursing, personal care attendants, equipment vendors, and occupational, physical, and speech therapies.⁴⁸ Some CMC may also routinely use rehabilitation centers and other post-acute care facilities; these community sites have been associated with decreased readmissions in hospitalized CMC.⁴⁹ Some hospitals, local areas, and states have initiatives to improve the integration of community care for CMC with hospital and outpatient care through home visits, telemedicine, and health information portals.^{50,51} The Royal Children's Hospital at Home program, in particular, educates and empowers family caregivers and community providers to deliver high quality of care to CMC in Australia that would otherwise require nearly continuous hospital care.⁵¹

Conclusions of Care Delivery for CMC

Given the available evidence and our own experience and intuition, the ideal care model for CMC should:

1. Permit access to urgent care in the outpatient setting to address health problems experienced by CMC before they become severe
2. Contain at least one provider who comprehensively understands and is capable of addressing all of a CMC's health problems, issues, and needs
3. Contain the capacity to coordinate care among all of the members of a child's care team, including community providers
4. Contain the capacity to assist with medical decision making and transitions while a child is hospitalized
5. Create effective, proactive plans of care to maximize the health of the child and to address future health problems before they occur

Part III

Economics of Care for Children with Medical Complexity

Children with medical complexity account for a disproportionate share of health resource utilization and cost. This disproportionate share occurs because the children:

1. Require health services from a myriad of inpatient, outpatient, and community providers
2. Rely on expensive medications, equipment, operations, procedures, and therapies to maintain their health
3. Experience frequent acute illnesses and chronic illness exacerbations that are difficult and time-consuming to manage

It is also believed that many CMC experience substandard care delivery and that this type of care contributes to wasteful utilization (e.g., unnecessary hospitalizations and emergency visits). The substandard care delivery received by many children with CMC is characterized by:

1. Fragmented and uncoordinated decision making
2. Poor health information management
3. Non-proactive (i.e., reactive) care planning and crisis-driven management
4. Over medicalization
5. Inadequate support of family caregivers

Health Care Utilization and Spending

Across the care continuum, it is believed that CMC account for as much as one-third of the total health care spending for all children.^{11,15} Hospital use accounts for the largest proportion (as much as 80%) of health care spending for CMC.^{11,15} The remainder of the spending is distributed among home nursing care (6-11%), outpatient provider visits (6-10%), pharmacy (3-4%), and emergency department visits (<1%).^{11,15} This breakdown in spending was determined from Canadian provincial health data¹¹ and Washington State health plan data.¹⁵ Total health care spending for CMC is heavily dependent on the child's severity of illness. For example, one study reported that the average total spending in 1999 dollars among CMC who have catastrophic or multiple chronic conditions ranged from \$6,800 for children with low severity to \$69,800 for children with high severity of illness.¹⁵

Most CMC use Medicaid and the use of Medicaid is increasing in CMC over time.^{15,18,52,53} Although there is variation in Medicaid reimbursement across states, it is believed that, in general, the cost of care delivery for CMC exceeds the amount paid from Medicaid for that care.⁵⁴ A large proportion of care coordination for CMC does not occur in traditional face-to-face health encounters and Medicaid does not typically pay for this type of encounter. Moreover, many hospitals that care for a large population of CMC on Medicaid might encounter a reduction in payment for substandard performance on inpatient quality measures.^{22,55}

Inpatient Utilization

Over the last decades, the rate of hospitalizations for children with CMC has doubled from 84 to 166 per 100,000 admissions of all children;⁴⁵ and CMC have accounted for an increasing, disproportionate share of inpatient health care utilization and cost compared with healthier children.⁴⁴ In 2006, CMC accounted for 10% of all admissions, 26% of all bed days, and 41% of all charges within all U.S. hospitals.⁴⁴

Patients who are enrolled in a structured clinical program that coordinates care for CMC experience, on average, 1.5 admissions per year, with a mean length of hospital stay per admission of 12 days.⁵² Neurologic impairment (57%) and presence of a gastrostomy tube (56%) are the most common clinical characteristics of hospitalized CMC program patients.⁵² Notable reasons for admission include major surgery (47%), medical technology malfunction (9%), seizure (6%), aspiration pneumonia (4%), vomiting/feeding difficulties (3%), and asthma (2%).⁵²

CMC have the largest impact on inpatient resources within children's hospitals. Over the last few years,

children's hospitals experienced more resource growth (i.e., a 33% increase in new patients from 2004-2009) in CMC than all other types of children;¹⁸ in 2009, these CMC accounted for 19% of admitted patients, 27% of hospital discharges, 49% of hospital days, and 53% of charges in children's hospitals.¹⁸ Cerebral palsy was the most common diagnosis and asthma was the most common co-morbidity observed among these CMC.¹⁸ CMC who have neurological diseases, like cerebral palsy, that are associated with severe impairment account for one-fourth of total hospital days and nearly one-third of inpatient charges within children's hospitals; the impact of these children has increased with time.²³

Unnecessary Utilization

It remains unknown how many hospitalizations and hospital bed days experienced by CMC could have been prevented with improved quality of care. Inpatient resource use that has been targeted as unnecessary or potentially preventable include: 1) hospital readmissions soon after a prior admission, and 2) hospitalizations for an ambulatory care sensitive condition or complication with a medical technology.

- Hospital readmissions account for over one-fourth of total spending for CMC.¹¹ Readmission rates are high for CMC who have multiple chronic conditions. Thirty-day readmission rates increase as the number of a child's chronic conditions increases: 5.4% for one chronic condition, 9.4% for two conditions, 12.4% for three conditions, and 16.8% for four or more conditions.²² CMC enrolled in a structured clinical program to help coordinate their care and meet their health care needs still experience 30-day readmission rates as high as 25%.⁵² These high readmission rates experienced by CMC are similar to the rates experienced by elderly Medicare beneficiaries.⁵⁶⁻⁶³
- The number of readmissions that CMC experience that could have been potentially-avoided remains unknown. Recent studies suggest that ~20% of pediatric readmissions could have been prevented with higher quality of care.^{64,65} The hospital discharge of CMC involves execution of a complicated array of care processes. We suspect that the quality of this execution is variable across hospitals. Preliminary data from an active quality improvement project suggests that some parents of recently discharged CMC feel that their child was actually not healthy enough to be discharged and that they do not have a good understanding of how to manage their child's health after leaving the hospital; children of these parents have a very high likelihood of readmission.⁶⁶

- Recurrent admissions (i.e., a series of admissions that occur close together in time) are one reason why CMC accumulate such a large share of inpatient resources. In a year's time, 3% of children admitted to a children's hospital will experience four or more additional admissions; the time between the admissions for these children is short [median 37 days (interquartile range 21-63)]. Because of their multiple admissions, CMC who are recurrently readmitted will account for nearly one-fifth of all admissions and nearly one-fourth of total inpatient charges within children's hospitals over time.⁵³ Anecdotally, quality improvement initiatives in some hospitals have broken the recurrent readmission cycle in CMC by increasing the use of post-acute care facilities after discharge and by creating discharge care plans that are meaningful and effective to keep the child healthy after discharge.
- Ambulatory Care Sensitive Conditions (ACSCs) are conditions that, if treated with timely and appropriate ambulatory care, may prevent a hospitalization.⁶⁷ For instance, in the primary care setting, appropriate asthma treatment coupled with the use of an asthma action plan may mitigate an acute asthma exacerbation and prevent the need for inpatient asthma care.⁶⁸ In CMC who experience five or more annual hospitalizations in children's hospitals, the percentage of their hospitalizations associated with an ambulatory care sensitive condition is 14.0%.⁵³ Asthma is the most frequent ACSC-related hospitalization (4%) in these children, followed by pneumonia (3%) and seizure (2%).⁵³ ACSCs were not created with CMC in mind; there may be other types of hospitalizations (e.g., hospitalizations for technology malfunction) that may be considered ambulatory care sensitive.
- Many children with CMC are assisted with medical technology that can stop working properly, become infected, or have unintended consequences on the health of the child. For example, a tracheostomy tube in a CMC with chronic lung disease can 1) crack and become ineffective at delivering air to the child; 2) become infected with bacteria that are difficult to treat; and 3) create ulcerations in the child's airway that can bleed. Hospitalization is typically required to manage and treat complications of medical technology like this. These complications can be avoided through proactive surveillance of the technology and proactive care planning that will detect a developing complication before it becomes life-threatening. The most common technologies used by CMC are gastrostomy tubes, tracheotomy tubes, and cerebrospinal fluid ventricular shunts.⁵²

Potential Cost Savings with Improved Quality of Care

It is suspected, but not proven, that providing high quality of care to CMC will result in substantial cost savings. Supporters of this notion hypothesize that the cost needed to provide high quality of care (i.e., coordinate care, develop effective and proactive care plans, and meet the health care needs of CMC) is offset by the cost savings achieved from reducing unnecessary health care utilization. The heterogeneity within CMC complicates efforts to evaluate this question; cost-savings observed in a complex care program with a specific referral pattern may not necessarily generalize to a broader sample of CMC identified through surveys or administrative data. Scalability of such interventions has yet to be established.

- In general, outpatient structured clinical programs providing high quality of care for children with medical complexity have not been profitable in a traditional fee-for-service payment arrangement. Reasons to explain the lack of profitability include 1) lengthy outpatient visits (e.g., a 1 hour visit) are routinely needed to address the health issues and care needs of CMC, and 2) a large percentage of the time spent on care coordination does not occur during face-to-face health care encounters; the extensive non-face-to-face time required to effectively coordinate care (e.g., with phone conversations, email, home visits, and health information review) is poorly reimbursed or not reimbursed at all.
- The potential value from coordinating care for CMC goes first to the patient and family (i.e., with improved health and well-being) and second to the payor (i.e., with decreased health care costs from less inpatient resource use). It is important to recognize that this value is not expected to occur for all CMC. There are many CMC whose health is expected to worsen rather than improve over time, regardless of the quality of care received by the child and family. For such children, the value of care coordination may be on the family unit rather than the child (e.g. by decreasing parental stress). Also, there are also CMC who are struggling with so many unmet health care needs that their hospital utilization and health care spending may dramatically increase once their needs are met with improved care coordination. Therefore, it is unreasonable to expect that all CMC will receive clear health benefits along with cost reductions from decreased health care utilization as a result of getting the care that they need.

Evidence of Cost Savings with Better Care

The evidence supporting an economic impact from clinical services that provide high quality of care to CMC is limited. Although the published literature, in general, shows a reduction in health care cost following enrollment into a specialized clinical service for CMC, most evaluations of the services have examined a narrowly defined group of CMC, have not included costs across the care continuum (e.g., home nursing, pharmacy, and out-of-pocket family expenses), and have not included a control group of similarly complex patients for comparison.⁶⁹ The absence of a control group, in particular, limits the strength of the findings from these evaluations. The same reduction in cost could have occurred in CMC who were not exposed to a specialized care coordination service because of the natural history of the CMC's clinical course and health care needs trajectory. Many clinical programs enroll CMC after the children have experienced a year of high inpatient resource utilization. It is unknown whether CMC with high inpatient resource utilization are more likely to have sustained or reduced hospital use in the future, regardless of their exposure to a complex care clinical program.

Listed below are several studies that assessed trends in health care cost and utilization for CMC before and after enrollment into a clinical program designed to coordinate their care, meet their needs, and optimize their health.

- An outpatient consultative program at the Children's Hospital of Wisconsin providing intensive care coordination for ~230 CMC reported a \$400,000 annual loss to operate the program, while contributing to a three-year reduction in hospital resource utilization of more than \$10 million for its patients.⁴²
- An outpatient primary care program for CMC at Arkansas Children's Hospital reported a one-year decrease in the mean annual cost per patient per month (PPPM) of \$1800 for inpatient care and \$6 for emergency department care. Although PPPM cost for outpatient claims and prescriptions increased, the overall cost to Medicaid PPPM decreased by ~\$1200.⁴¹
- Two community-based pediatric clinics in Canada staffed with tertiary-care nurse practitioners to coordinate care for 81 CMC reported a mean [standard deviation (SD)] decrease in PPPM total health system cost from \$244 (SD 981) to \$131 (SD 335) without an increase in out-of-pocket costs to families. Fewer inpatient days was the primary reason for the decrease in PPPM. Child quality of life improved after enrollment in the clinic intervention.⁷⁰
- A care coordination intervention for ~150 CMC/CSHCN that included a case manager, parent consultant, and an individualized plan of care within six primary care pediatric practices in Massachusetts was associated with a decrease in hospitalization rate (58% to 43%) and a decrease in the rate of parents missing three or more weeks of work (26% to 14%).⁴⁰ The intervention cost \$400 per patient.
- A medical home for ~30 CMC at University of California Los Angeles that offered an hour-long intake appointment, 30 minute follow-up visits, access to a family liaison, and a family notebook reported a decrease in the average number of emergency department visits from 1.1 (SD 1.7) to 0.5 (SD 0.9) after enrollment.³⁹
- Two CMC program evaluations are currently under evaluation in separate randomized clinical trials in Texas.^{71,72} The publication of these results is eagerly anticipated.

Conclusions for Economics of Care for CMC

Although the evidence to support cost savings from improved quality of care for CMC is promising, additional analyses are needed before accurate projections in cost savings can be derived.

Part IV

Conclusions and Next Steps

It is clear that substantial work needs to be done to determine how to maximize the health and well-being of CMC and how to provide high quality of care to them. As this work is completed, providers will continue to battle their way through an evolving health system while trying their hardest to meet the needs of the children and to ease the heavy caregiving burden experienced by many families of CMC. Despite that effort, a large proportion of care will continue to rest, inappropriately, on the shoulders of the family caregivers who've been picking up and carrying the dropped pieces of their child's care. It is time to push the field forward and make substantial improvements in the ecology of care for CMC and their families. To make that happen, several key questions need to be addressed:

Which CMC, and by what definition, will benefit the most from improved models of clinical care delivery?

The major issue with a definition for CMC, as previously mentioned, is that administrative data (e.g., diagnosis codes) do not provide enough information on the health

and family needs of CMC to determine the true opportunity for improvement. Surveys have the potential to add in this highly valuable information to identify CMC, yet they are expensive to implement on a large scale. As population-based clinical and payment interventions for CMC are implemented, a detailed assessment of CMC's health, familial, and social needs should occur. This assessment should include an analysis that correlates these needs with the child's underlying chronic conditions and attributes of the child's existing health care team. This information will help delineate which CMC are most likely to have unmet needs and/or deficits in their care team; these children may be the most likely to benefit from improved quality of care.

What is the best, most effective model of care delivery for CMC?

As the definition of and the approach to identify CMC are perfected, efforts to improve care for CMC should not be put on hold. There is a critical need to identify the structure and processes of care most important for CMC and to describe, in rich detail, how those attributes have been successfully operationalized and implemented. Many providers in hospitals, rehabilitation and long-term care facilities, primary care clinics, specialty clinics, case management programs, home nursing agencies, and other care sites are currently deeply rooted in caring for CMC and have been so for a long time. There is an urgent need to share lessons learned and knowledge gained from their experience. Health information technology solutions (e.g., patient portals and telemedicine) should be included in those discussions. Some models of care delivery may work well for some CMC but not others; one over-arching model may not fit all CMC. The model that works best for CMC with a liver transplant may not be as effective for CMC with severe neurological impairment. Specific components of clinical care delivery for CMC that are hypothesized to be effective (e.g., access to urgent care, care coordination, and proactive care planning) should be formally evaluated in multi-centered studies with a large enough cohort of sites to identify best practices. Standardized methods to measure these care components should be developed. Creative ways to define appropriate control groups in these analyses should be explored. Knowledge of the critical structures and processes of care for CMC will permit greater spread of effective care delivery.

How much cost savings can be achieved by improving care for CMC?

Evidence to support cost savings from improved quality of care for CMC is promising. However, an additional set of analyses is critically needed before accurate projections of cost savings can be derived. More information is needed on the natural trends in utilization and cost for

CMC across the health care continuum (i.e., inpatient, outpatient, and community care), including a description of utilization and cost before and after a CMC experiences a period of high-intensity resource utilization, derivation of models that predict future cost and utilization for CMC based on prior health care utilization patterns and clinical attributes, and delineation of CMC who have predictable vs. unpredictable cost and utilization over time. Without these analyses, hospitals, health systems, and states might be at risk for establishing erroneous targets for care quality, utilization, and cost savings for CMC.

What is the best way to teach familial caregivers and pediatric providers how to care for CMC?

As best practices for CMC are identified, educational curricula and learning collaboratives should be implemented to support the development and growth of the familial and clinical workforce trained to serve CMC. A myriad of providers work in the field of complex care, including general pediatricians, hospitalists, intensivists, physiatrists, developmental and neurodevelopmental pediatricians, and palliative care providers. Moreover, CMC rely on many allied health professionals, including home and school nurses, social workers, case managers, therapists, and family navigators that need to have core competencies in complex care to deliver high quality of care. Overall, there is an urgent need for trainee and continuing education in complex care across the care continuum.

Which initiatives to reform health care payment and policy will benefit CMC the most?

Several health care payment and policy changes/initiatives currently in practice or soon-to-be implemented could dramatically affect care delivery for CMC.⁵⁴ Elimination of pre-existing condition restrictions, annual and lifetime caps in insurance coverage, and standards for essential health benefits might push private insurers to play a larger role in care delivery for CMC. Funding for the Children's Health Insurance Program (CHIP) may expire in 2015; if the funding is not renewed, then many CMC may be pushed toward or transitioned into the new Health Insurance Marketplaces (i.e., exchanges). Some state Medicaid programs are reducing provider reimbursement and instituting utilization controls that could affect the ability of CMC to get access to needed services while other states are implementing Health Home demonstrations and Center for Medicare and Medicaid Innovation (CMMI) projects interventions that might improve access to care and services for CMC. It will be important to closely monitor all of these activities as health system reform for CMC is pursued.

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