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Abstract

Children with medical complexity (CMC) represent a small percentage of children overall, but account for a disproportionate percentage of pediatric medical expenditures. CMC and their families have specific needs related to the chronicity of their medical and developmental conditions which require expertise in management, and a broad range of needs for subspecialty care, therapies and ancillary services. What's more, their care is time consuming and, often, management of their non-acute needs is poorly reimbursed. A number of novel programs have emerged to address the special needs of this important population of children. These programs are diverse, but have in common the provision of comprehensive and coordinated care, emphasis on enhanced communication between all providers and caregivers, improved patient access to all needed elements of care, and proactive anticipation of a child's potential problems and functional limitations. Examples of both ambulatory and inpatient models are outlined in this chapter. There is no single idealized model of care for all CMC. Instead, elements of the models discussed can be applied to a given system's resources, personnel, patient needs, and population to construct a model that will best fit a given situation.

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Introduction

Children with special health care needs (CSHCN) have been defined by the Maternal and Child Health Bureau since 1998 as those “who have or are at increased risk of a chronic physical, developmental, behavioral, or emotional condition, and who also require health care and related services of a type or amount beyond that required by children generally” [1, 2]. According to the 2009–2010 National Survey of CSHCN, 15.1 % of all US children (11.2 million) are CSHCN, and 23 % of households report having a CSHCN (Figs.18.1 and 18.2) [3]. This broad definition encompasses children with a wide range of chronic medical conditions such as sickle cell anemia, diabetes and asthma as well as those with psychiatric and behavioral developmental disorders such as learning disabilities, attention deficit, mood and autism spectrum disorders. When compared to their age-matched peers without special healthcare needs, CSHCN have more functional limitations and utilize more medical, mental health, educational and rehabilitative services, and prescription medications. They are also at higher risk of school absence [1], hospitalization and intensive care admissions [1, 2] and of being affected by medical errors [2, 3].

Caitlin is a 14 year old girl with spastic quadriplegic cerebral palsy, intellectual disability

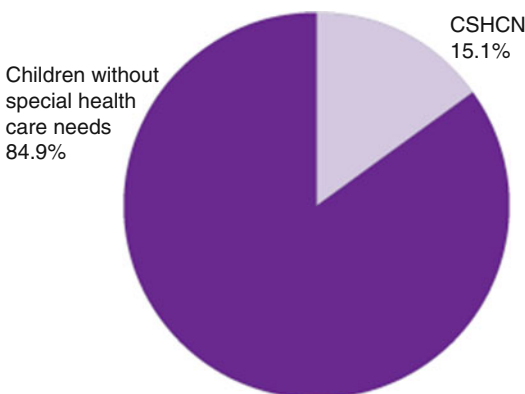
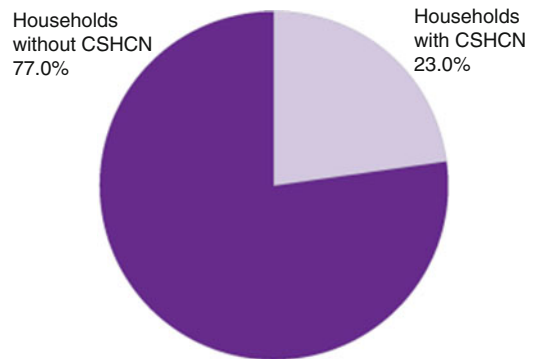


Fig. 18.1 From US Department of Human Services HRaSA, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2009–2010. <http://mchb.hrsa.gov/cshcn0910>



*Includes only households with children.

Fig. 18.2 US Department of Human Services HRaSA, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2009–2010

and a seizure disorder who has entered her adolescent growth spurt with progression of her neuromuscular scoliosis and worsening chronic lung disease. Caitlin has a g-tube for hydration and nutrition as well as GI dysmotility, chronic constipation and gastroesophageal reflux disease. She needs spinal fusion to halt her curve progression, but this is a decidedly complex surgery and the related risks and benefits must be collaboratively considered among her family and multiple health-care providers. Caitlin attends an interdisciplinary cerebral palsy clinic where she can see the many members of her health care team on the same day. The decision regarding whether or not to pursue surgery and team discussions to minimize peri-operative risk are made easier by having all of her providers in one location, enhancing communication and shared decision making. Caitlin’s situation involving multiple subspecialists and needing heightened care coordination is common for children with medical complexity.

Children with medical complexity (CMC) represent a subset of CSHCN. CMC are those with chronic, severe health conditions, substantial health service needs, major functional limitations and high health resource utilization [4]. CMC typically have acquired or congenital multisys-

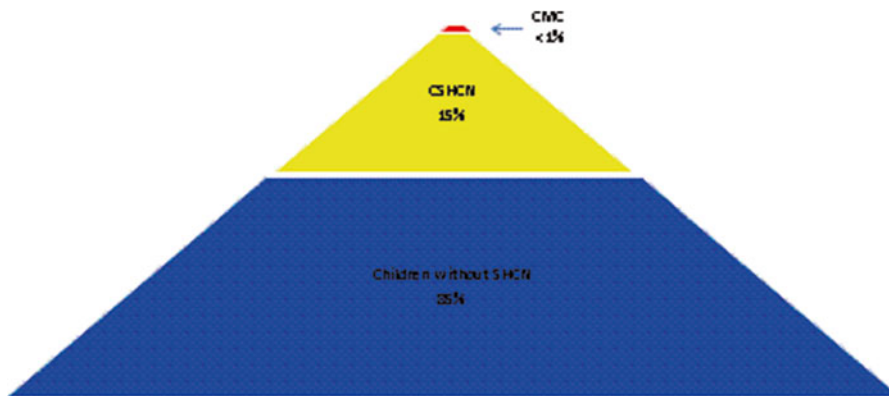


Fig. 18.3 Prevalence of children with medical complexity

tem diseases associated with disabilities and technology dependencies [5]. Although they represent less than 1 % of all US children (see Fig. 18.3), they account for as much as one-third of total child health care expenditures [4] and are at high risk of adverse medical, developmental, psychosocial and family outcomes [6]. With continually improving healthcare technology, the prevalence of CMC is on the rise [7]. More children survive disorders that were once fatal, but are left with serious chronic conditions and disabilities.

All CSHCN require reliable, comprehensive, coordinated health care to help them and their families navigate the complexities of their needs, whether it be prescriptions, communication with subspecialists, educational plans, specialized therapeutic services or durable medical equipment. Although the medical home is the primary care model ideally designed to deliver this comprehensive range of services, more than half of CSHCN (53 %) lack medical homes [8]. CMC require substantially greater amounts of time, expertise and resources to achieve optimal health outcomes [5]. They are especially dependent on acute care resources, subspecialty care, and care coordination services [5, 7, 9].

Because of the high cost and resource utilization of CMC, exploring new models of care for this population, with a major emphasis on care coordination, has the greatest potential to reduce costs, improve efficiency of health care use, and reduce family stress [10]. What follows is a

review of current care models for CMC both in the outpatient and inpatient settings. No one model is ideal, as resources and needs vary widely with geographic and population demographics. Additionally, models need to be adapted to a wide range of settings, from rural primary care practices to urban tertiary care hospitals. What is critical is that each model be tailored to the needs of the children and families served, aligned with organizational cultures, and based on systematic approaches with measureable outcomes of impact. Each model should deliver expert healthcare with coordinated communication among all stakeholders, create individualized care plans that maximize quality of life and reduce costly duplications in resource utilization, and, when possible, offer educational opportunities to healthcare providers for CMC.

Coordinated Care in the Ambulatory Setting

Historically, the primary care pediatrician has been at the center of outpatient care for CMC. Models of care vary based upon multiple factors including availability of local resources, number of CMC in the practice and region, and experience level of the individual provider.

However, as the number and complexity of CMC have increased, significant barriers have arisen that make it challenging for the primary care pediatrician to provide quality

comprehensive care to this population. Barriers often cited include a lack of familiarity with conditions common in CMC, lack of time in a busy primary care practice, lack of ancillary resources, and low reimbursement rates relative to time spent with CMC [11]. Additionally, a significant amount of care for CMC takes place in tertiary care inpatient settings where a large percentage of primary care pediatricians may not hold privileges or actively engage in inpatient care. These barriers can disrupt continuity of care, break down communication among multiple providers and sometimes leave unmet needs based on erroneous assumptions that someone else is addressing a given need of the patient or family.

Because of the limitations inherent in traditional models of healthcare delivery for CMC, alternative models have emerged with the goal of promoting quality comprehensive care for CMC. Depending upon resources available,

ambulatory models can vary from an individual rural provider, to a primary care gatekeeper, to an interdisciplinary clinic. Furthermore, care may be community or hospital-based. The most common models include the medical home, case management, and variations of consultation (see Table 18.1).

The Medical Home Model

The medical home model has become the most widespread outpatient care delivery model for CHSNC. In theory, the medical home could become the ideal model of outpatient care for CMC as well. The medical home model has been defined by the Agency on Healthcare Research and Quality (AHRQ) as including the following five primary components [12]:

Table 18.1 Ambulatory models of care for CMC

Model type	Setting	Advantages	Disadvantages
Medical home	Primary Care Office	Ease of access	Subspecialty care unavailable
		Urgent and continuity needs met	Ancillary care often unavailable
		Comprehensive general care	
Case management	Primary Care Office	Ease of integration into existing setting	Poor reimbursement
	Tertiary Center	One point of contact for parents	Added expense
	Governmental Agency	Increased cost efficiency	Case manager usually cannot directly provide care
	Insurer		
Consultative	Tertiary Center	One point of contact for parents	Poor reimbursement for indirect care
		Consolidation of care	Significant startup costs
		Fewer appointments leading to decreased school/work absenteeism	Continued need for other subspecialists
			Lacking primary care functions
Multi-disciplinary clinic	Tertiary Center	Consolidation of care	Payor restrictions on reimbursement
		Decreased duplication of services	Scheduling difficulties
		Fewer appointments leading to decreased school/work absenteeism	

The Medical Home Team

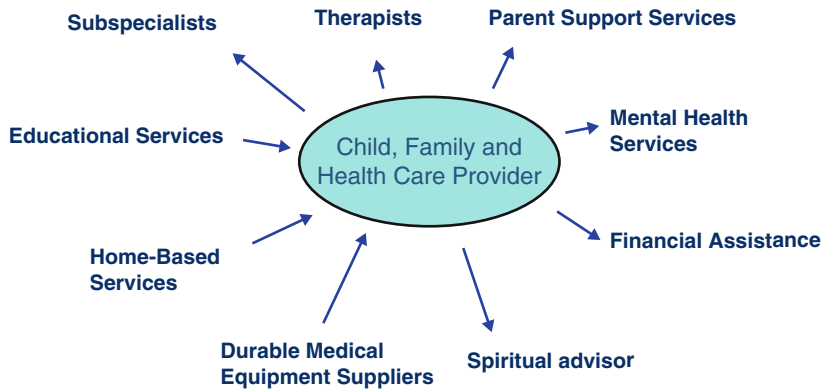


Fig. 18.4 The Medical Home Team

- **Comprehensive care.** The medical home should be capable of providing the majority of a given patient's care needs. This will include mental health, well care, acute/urgent care, and common ancillary services such as case management, nutrition, and social work.
 - **Patient centered care.** The medical home model recognizes that patients and their families are an integral part of the healthcare team. Care must be given with respect and familiarity for each patient's individual spiritual, social, ethnic, and cultural values.
 - **Coordinated care.** Medical home model practices strive to coordinate care across the healthcare continuum, including hospitals, home health providers, ancillary care providers and specialty consultants.
 - **Accessible care.** The primary care medical home should be capable of care delivery with short appointment wait times, 24/7 access to information, and easy access to providers for questions or concerns.
 - **Quality and safe care.** Primary care medical homes should have a high commitment to providing high quality of care. This commitment should be acted upon by having methods in place to recognize, measure, report, and implement quality improvement initiatives and methods to measure and improve patient satisfaction.
- Within the medical home, coordination of care is co-localized and shared amongst a number of personnel who both provide and/or coordinate care. The number of participants in the team of a child with complex medical needs can be great, and systems to target coordination between so many loci of care for the child are extremely important (see Fig. 18.4). CMC in an effective medical home have been found to have decreased hospitalizations, decreased emergency department utilization, decreased school absenteeism, increased sub-specialist access, and decreased subjective unmet family needs [8, 13, 14]. Medical Home implementation has also been shown to increase value driven outcomes of better care, better health, and lower healthcare costs. It has been shown to generate substantial short and long term cost savings to patients, employers, private health plans, and public healthcare systems [15, 16].
- Tanner is a 7 year old boy who was born at 28 weeks gestation. His ongoing medical conditions include mild pulmonary hypertension complicated by asthma, seizures, poor growth, attention deficit disorder, and global developmental delays. His primary care pediatric office is Medical Home certified. In addition to his pediatrician, the office has a nurse case manager who helps to coordinate Tanner's

appointments, handles insurance issues, manages his home health orders, and facilitates communication among Tanner's providers. When Tanner had pneumonia last fall he was able to avoid hospitalization because his pediatrician communicated with his pulmonologist, enhancing his acute plan of care, providing antibiotics based on Tanner's most recent sputum culture found in the hospital lab system, and his nurse case manager ordered him a suction machine to help manage his increased secretions.

The primary advantage of the medical home model is that by being primary care based, it may be more accessible to a given patient and care is more likely to be comprehensive in nature. The leading disadvantage is that primary care providers are unlikely to be able to provide all care that a CMC will need, such as subspecialty care, physical/speech/occupational therapies, and homecare resources, thereby making completely comprehensive care impossible.

Children with medical complexity who live in rural settings possess a set of unique obstacles to obtaining quality healthcare. These obstacles include scarcity of primary care pediatricians, absence of sub-specialty providers, lack of pediatric specific ancillary services, long travel times to specialty centers, and increased caregiver time requirements related to medical care activities. These obstacles are often compounded by socioeconomic factors such as higher rates of poverty, increased under or non-insurance, lower parental education rates, and higher caregiver unemployment rates seen in rural areas [17]. These issues increase the likelihood that CMC from rural settings will receive fragmented, more costly, and lower quality healthcare than children in areas of higher population density. When applied to children in rural settings, the medical home model has been shown to improve care satisfaction, decrease parental missed work days, patient missed school days, and increase access to care [18].

Case Management Model

Case management models involve a trained individual, usually a social worker or nurse, to assist the child's healthcare providers in planning, coordinating, executing, and following through with the child's healthcare plans. The case manager may be located within a primary care practice, within a state based agency, attached to a tertiary care center, or even as a service of a third-party payor. As with the medical home model, the emphasis is on comprehensive coordination of care, increased quality of care, and decreased healthcare costs but, unlike the medical home model, case management is uncoupled from direct patient care. In this model, the case manager is assigned to a set of patients and is responsible for coordination of care among a number of different healthcare providers and delivery settings.

Rose is a 5 year old girl with tuberous sclerosis who lives in a rural setting 5 h away from the nearest tertiary care center. Her seizure disorder requires multiple medications, a ketogenic diet, and a vagal nerve stimulator. Her condition is complicated by autism spectrum disorder and significant developmental delay. A case manager provided through the Department of Developmental Services has been extremely beneficial in coordinating care between her sub-specialists, local primary care physician, home health service, and behavioral and educational therapists. In particular, when Rose needed to start home-based applied behavioral analysis therapy, her case manager spoke with her pediatrician to obtain much needed documentation and advocacy for service delivery through the appropriate state agency. Rose's parents are overwhelmed trying to maintain their jobs and meet all of Rose's needs. They very much appreciated the assistance in completing applications and collecting the required documents for this important service for their daughter.

Use of case management has been shown to decrease hospital utilization, increase outpatient care access, and decrease overall cost of care [19]. Advantages of the case management model include its ease of integration into diverse practice settings, the designation of a point person for all the needs of a patient or family and the ability of one case manager to work with multiple providers in a variety of settings and locations, thereby leveraging the case manager's impact. Disadvantages include poor reimbursement for case management (particularly in a fee-for-service setting), challenges of funding a shared case manager, and the fact that although the case manager is often directing care, providers and resources still need to be available in the area to which care can be directed. Additionally, case managers and the providers that they work with may not always be of the same opinion regarding specifics of patient care, and these differences may negatively impact care delivery.

CMC Consultative Model

In consultative models of care for CMC, a specialized provider or group of diverse providers is assembled to work in conjunction with the patient, the family and the primary care provider towards providing integrated healthcare. This arrangement often takes the form of a specialty clinic where diverse providers follow populations of CMC over time and coordinate care between a given patient's primary care provider and the patient's multiple sub-specialty providers. These specialty clinics can be tightly defined by specific disease conditions (e.g. a clinic for spina bifida patients), or loosely defined to include all CMC patients in a system. Comprehensive care model clinics can be staffed by generalists such as pediatricians or pediatric nurse practitioners, or by sub-specialists such as neurologists, physiatrists or surgeons. Depending upon local personnel resources and patient needs, a combination of these strategies may be used.

Aiden is a 2 year old boy with complex congenital heart disease, chronic lung disease, spastic

cerebral palsy, shunted hydrocephalus, seizures and developmental delays. In the past, his parents have been frustrated that when one subspecialist makes a change it impacts many other aspects of his care. In order to better coordinate his care in one location, he was referred to a complex care clinic at the tertiary care hospital. There, many of his conditions are managed simultaneously with input as needed from his subspecialists, whom his complex care provider can access more readily than his pediatrician can being based in the community. Aiden's complex care doctor communicates regularly with his pediatrician, and his pediatrician can reach out to the complex care specialist when he needs assistance or expertise in certain aspects of care management.

Advantages of a consultative model include the provision of a touch point of centralized care and information for families as well as healthcare providers. It allows less disruption of parent work and patient school schedules by potentially providing a place for CMC to see multiple providers in a single day of visits, and improves transition from outpatient to inpatient care. The primary disadvantages of the consultative model include the startup costs for a healthcare system and poor reimbursement for the relative time demands of CMC in a fee-for-service environment. Although often lacking in strong study design, most evaluations of consultative models of care demonstrate improved family perception of quality of care, decreased parental anxiety surrounding care of the CMC, and overall cost savings both to the family and the healthcare system.

Specialty-Based Consultative Model

Subspecialty based models are typically either single specialty or interdisciplinary clinics targeting a certain condition instead of the traditional single specialty/organ system approach. Often, because of their broad specialty nature, these programs evolve in hospital settings. Examples of a single subspecialty model clinic would include

bone marrow transplant clinic, cystic fibrosis clinic, or a juvenile arthritis clinic. These clinics are staffed by physicians from a given single specialty (e.g. oncology, pulmonology, and rheumatology) with concurrent care provided by ancillary providers such as social work, nutrition, and respiratory therapy. Examples of interdisciplinary subspecialty models include spina bifida clinics (staffed by neurology, general pediatrics, urology, gastroenterology and neurosurgery), tracheostomy-ventilator clinics (staffed by pulmonology, otolaryngology, physical medicine, respiratory therapy, and social work), or Down Syndrome clinics (staffed by cardiology, developmental/behavioral pediatrics, nutrition, physical therapy and social work).

Jane is a 3 year old girl with hypotonicity related to an unspecified metabolic disorder. She relies on a tracheostomy and ventilator to manage her chronic respiratory failure. She has chronic lung disease, dysphagia, a seizure disorder, failure to thrive and hip dysplasia. She is seen in a multi-disciplinary ventilator management clinic where she is seen simultaneously by respiratory therapy, pulmonology, otolaryngology, physiatry, nutrition, and general pediatrics. As travel with her all of her equipment is difficult, the parents feel that consolidation of her visits is a substantial benefit.

Advantages of the subspecialist model include co-localization of providers with improved communication and coordination of care, decreased school and work absenteeism, increased likelihood of parent follow through with treatment plans, and decreased duplication of services [20]. A study looking at the impact of disbanding an interdisciplinary myelomeningocele clinic showed that a significant proportion of patients failed to maintain adequate follow up, and experienced subsequent negative health impacts [21]. Potential disadvantages of the model include restrictions on payment, difficulties with scheduling, exclusion of other providers involved in the CMC's care, prolonged time spent in clinic, absence of primary care functions such as urgent

care and vaccinations, and decreased family choice in healthcare providers.

Coordinated Care in the Inpatient Setting

The inpatient environment offers different opportunities and challenges in the care of CMC. Because these children are at high risk for complications and account for a substantial proportion of inpatient resource utilization, the development of models of hospital care requires careful and informed attention [3, 8, 11]. Several models currently exist in the United States, some of which are well-established and others which are nascent. These include the traditional, the consultative, the case management and the complex patient specialty models. (see Table 18.2).

Traditional Model

The predominant model of inpatient medicine in the United States is typically organized according to level of acuity (intensive care units, step down units, general floors), patient age (pediatrics or geriatrics), or specialty (surgical vs. medical issue). Patient placement occurs according to the area of expertise of the nursing and physician staff, patient resources required, and likely need for intervention. However, CMC are typically intermixed throughout inpatient areas as they do not fit easily into one of these general patient care categories. Additionally, the dynamic and interdependent nature of multi-organ system conditions frequently results in exacerbation of co-morbidities following any acute changes. Without specific attention to these complex phenomena, complications and poor outcomes can occur. Often, it is only after an acute deterioration or lack of improvement that attention is turned to patient co-morbidities.

Jessica is a 15 month old girl with an underlying chromosomal duplication, a ventriculoperitoneal (VP) shunt and severe tracheomalacia admitted to the hospital for shunt failure.

Table 18.2 Inpatient models of care for CMC

Model type	Advantages	Disadvantages
Traditional model	Non-disruptive to current health care system	Variable CMC expertise
	Can utilize traditional staffing and operations model	Unclear roles and accountabilities
	Financially viable in fee for service model	Burden of care coordination transferred to family, primary care physician Limited communication between inpatient team and community provider Care coordination done on an ad hoc basis
Consultative model	Provides CMC-specific expertise	Poorly defined ownership of clinical problems
	Ensures some standardization of care	Variable inclusion at key decision points
	Opportunity for training of other caregivers	Lack of a cohesive plan of care
	Can assist with integration between providers	Variable financial viability with co-management models
Case management model	Removes time-intensive responsibilities from providers	Coordination of care separated from clinical care
	Coordination by those with expertise and ties to community resources	Fragmentation of care at points of transition (in-hospital transfer & discharge)
	Streamlined & efficient	
	Improved communication with family and community	
Specialty CMC team model	CMC Care can be standardized	Risk of staff burnout
	Care coordination within team by non-MD	Further subspecialization of staff
	Ownership of problems	Potential need for higher MD/RN staffing ratios and cost increase
	Defined point person for decision making and communication	
	Allows risk stratification	

Following replacement of her VP shunt and recovery in the ICU for 5 days, she is now stable for transfer to the general wards under the care of the neurosurgical service. Jessica develops increased work of breathing with stridor in the subsequent days and the neurosurgical service requests transfer to the general pediatrics service for ongoing care. A CXR reveals areas of atelectasis and Jessica receives increased pulmonary toilet with return to her baseline.

In the traditional model, the patient's most pressing needs are addressed with more limited attention

devoted to time intensive coordination of care. Thus, the burden of care coordination is often transferred to the primary care physician, the family or an outside facility at the time of discharge. A particularly important challenge in the traditional model is communication between the inpatient teams, family and community providers regarding potential problems or general goals of care [22, 23].

However, as the predominant model, this traditional model has a number of attributes. It is non-disruptive to the health care system present in most hospitals and requires minimal additional resources. Traditional staffing models and hospital operations can be utilized. Finally, it is a

financially viable model in the fee for service financial environment, providing a relative steady stream of hospital occupancy and revenue. Yet, there are inherent disadvantages to this traditional model of inpatient care, including broad ranges of provider expertise, lack of standardization of care processes, and unclear roles and accountabilities in care delivery, often contributing to family dissatisfaction and fragmented care [11, 24, 25].

Consultative or Co-management Model

Although far from common, consultative teams for CMC are cropping up in tertiary care settings. Such teams are often staffed by general pediatricians, but may be staffed by specialists in neurodevelopmental disabilities, developmental behavioral pediatrics or other areas of expertise, and often include physicians as well as nurse practitioners. CMC consult services assist with a particular aspect of care or can be co-managers of medical care [26].

Joseph is an 8-month-old former 26-week pre-term infant with intraventricular hemorrhage and cerebral palsy, chronic lung disease, and gastrostomy tube dependence now admitted to the hospital with respiratory distress. He was discharged recently from the NICU on full gastrostomy feeds, but has been vomiting and is admitted to the GI service. A gastric emptying study is normal, gastroesophageal reflux medications are maximized, and feeds are changed to continuous rather than bolus delivery, yet there is no improvement in retching and vomiting and there is mild respiratory distress. A consultation is requested from the CMC consult service and further evaluation reveals a significant hypercarbia with aerophagia and abdominal distension as an underlying cause of the respiratory distress and feeding intolerance. The infant is started on continuous positive airway pressure (CPAP) at night and bolus feeds during the day with improved weight gain and tolerance of feeds.

The CMC consult model ensures some standardization of care, which likely improves efficiency and safety [27]. In teaching hospitals it also offers the opportunity for trainee education. This is a common and successful model of care for surgical patients in many ICU's, with the CMC consult team helping to integrate information from multiple involved specialists, including medical and surgical teams, and providing specific expertise around the care of complex children. However, this model can have a number of limitations, including poorly defined ownership of clinical problems, critically important in urgent situations and times of transition; lack of a cohesive plan of care; and variable financial viability with co-management models [25].

Case Management or Patient Representative Model

The case management and patient representative models are variations of the traditional model of care for CMC. These models allocate the coordination of care at time of discharge or hospital transitions to case managers or patient representatives, separating it from clinical care. Applauded by many health-care providers, this removes many time intensive, non-clinical responsibilities from clinical care providers and re-allocates them to team members with expertise and access to resources for care coordination.

Bethany is a 16 year old girl with myelomeningocele, a VP shunt, neurogenic bowel and bladder who is admitted to the hospital with a large decubitus ulcer requiring surgical debridement and IV antibiotics. Having a single parent who works full time at night and a bedroom on the second floor of the house complicates her home situation. As this is her second significant decubitus ulcer in the last year, her case manager takes on the role of locating housing with fewer architectural barriers, a pressure reducing mattress and wheelchair cushion, and skilled home nursing visits for Bethany while she remains in the hospital for her initial wound care.

The case management model designates a point person for coordination of care and can result in a more streamlined, efficient process with direct advocacy for the patient. It allocates the role of care coordination to personnel with ties to both community and hospital resources, rather than being done on an ad hoc basis for each patient. However, these processes can sometimes occur outside of acute care, separate from the core medical team and may result in fragmented care at points of transition, including discharge. A critical aspect of case management includes communication with the primary team in the community to ensure continuity of care in that setting, to promote safety and reduce risk of hospital readmission [28].

Complex Patient Specialty Team

It has long been recognized that care can become fragmented when multiple providers are directing care in a child with complex medical problems. To provide more fluid coordination of care and expert medical management, CMC-specific care teams have begun to emerge in the United States. This is a relatively new model that involves cohorting CMC onto teams that are often led by hospitalists [29, 30]. Two variations have developed: a nursing cohort model with CMC grouped on specific nursing units and another involving specific care teams dedicated to CMC. In the latter model of CMC focused teams, the primary team, often including a specialized care coordinator and social worker, provides both the acute care needs and coordination of care [31].

Mary is a 13 year old girl with cerebral palsy, encephalopathy and GT dependency who is admitted to the hospital for the evaluation of unexplained irritability for several weeks despite repeated ambulatory evaluation. She is afebrile, has had no recent feeding intolerance and has no focality on exam, but is having periods of moaning and obvious discomfort. She is admitted to a specialized service dedi-

cated to the inpatient care of the complex pediatric patient. Mary is evaluated in a step-wise fashion for likely causes of her pain. A skeletal survey reveals several lumbar compression fractures and she is evaluated by the Orthopedic service and started on anti-inflammatories and log rolling with improvement. She is discharged to home with vitamin D and calcium supplementation as part of her home care regimen.

The dedicated care team model has several distinct advantages. Specific expertise is developed within a finite and consistent group of health care providers. Care coordination is provided by this group in association with appropriate personnel who are integrated into the team and not allocated to a third party. There is ownership of the many medical problems and therapies, and families have a defined point person for decision-making and information. A service that specifically provides medical care and coordination for the CMC can be an invaluable resource for other services within the hospital and has the potential to become an established standard for children requiring input from multiple providers.

This model is further improved by utilizing nursing cohorts. Similar to other nurse cohorting practices in the hospital (post-operative patients, patients with cardiac disease or cancer), the specificity of the patient population allows development of nursing staff expertise, standardization of care for these challenging patients, and allocates care responsibilities to those with interest and expertise.

Disadvantages of this model are similar to those seen in other cohorting models. These include further subspecialization of medical and nursing staff; risk of staff burnout from only caring for patients with highly complex, often unsolvable needs; and potential need for higher nurse/patient staffing ratios and resulting cost increase. Cohorting may provide a mechanism to measure risk stratification in CMC, allowing improved outcomes, and may help preserve fixed hospital resources, which play a role in controlling healthcare cost.

Models of the Future

As described above, a multitude of unique models of care for CMC have emerged. However, healthcare must undergo a seismic shift before revolutionary models of care can be successfully implemented for these children with high medical complexity and fragility. Ambulatory care, including the evaluation and management of children with chronic conditions and disabilities, will need adequate compensation [32]. Additionally, information technology will need to play an increased role in care coordination (knowledge sharing, fact based decision making, feedback mechanisms) [33]. Without these cornerstones of change, the long-term sustainability of innovative models is unlikely.

Traditional models are largely built around a “one size fits all” delivery of care. Each patient is viewed as a new and unique experience and visits include a doctor, a nurse and ancillary services. Rather than a patient visit including most personnel on a care team (an assistant, a nurse, a doctor, a social worker), another option could include stratifying service according to need. For example, services provided may only include appointment coordination with a scheduler by telephone, a home visit with a social worker for discussion of housing needs or guardianship, or a video chat with a nurse about feeding issues. This model could include standardization of service for common problems, yet provide a customized program for any individual patient.

The current medical paradigm for CMC includes both acute and chronic problem solving and is primarily physician based. As the majority of physician training is targeted at diagnosis of acute illness rather than the management of chronic conditions, new models using physicians differently are likely to emerge. Physicians would evaluate CMC with new and acute problems, while non-physicians with MD oversight attend to more chronic issues. This is likely to result in more efficient and standardized care that better utilizes the skills of personnel. There are also opportunities to enhance medical education with exposure of trainees to issues in chronic care.

An example emerging outside of traditional healthcare model is the retail clinic model. Non-physicians using a rules-based model attend to specific acute and chronic health conditions. Only those patients that fulfill pre-determined criteria are seen by an NP or RN [34]. This model has a proven success record when carefully developed and has been shown to deliver care with higher quality at a lower cost and provides another potential model for CMC.

Telemedicine is a rapidly growing model of care for patients outside of the hospital setting. As travel for CMC is generally more challenging, telemedicine could revolutionize the ambulatory experience for these children. It would allow improved post-discharge monitoring, troubleshooting of acute problems and allow co-management of patients in the community or other hospitals. Although disruptive to the current model of healthcare, it will likely be well accepted by patients and families who must balance work and school disruption, as well as travel expense.

Another new model being introduced in the ambulatory realm is that of group visits. Some of the day to day problems of chronic care might be better served by visits with other families for traditional education, enhanced by shared learning from one another. An example could involve participation in a gastrostomy tube clinic where families meet to learn pre-operative concepts, post-operative g-tube maintenance and common troubleshooting.

At present, the primary focus of pediatric inpatient medicine is acute care management while chronic disease management occurs on an ambulatory basis. CMC with their multiple medical conditions offer a unique opportunity to alter this model, addressing some of the more chronic issues while patients are admitted to the hospital [35]. For example, an admission of a 4 year old with an exacerbation of seizures could also include a wheelchair fitting, family education on suctioning technique and pre-operative planning for gastrostomy tube placement. A child admitted for pneumonia may have a modified barium swallow study to assess aspiration risk and receive

input from nutrition and speech pathology about dietary modification to prevent recurrent episodes rather than simply receiving antibiotics to treat the acute episode. By reimbursing chronic care in the acute care setting, attention to less acute problems that lead to frequent readmissions could occur and overcome many of the difficulties that occur upon discharge [36].

A unique model in the adult population has emerged to provide acute hospital level of care in the home [37]. Although not yet implemented in children, this type of program delivers health care entirely in the home and not in the traditional inpatient setting. Again, using rule-driven models, some CMC with specific acute illnesses could be managed entirely on an ambulatory basis. For example, a 17 y.o. with myelomeningocele and multiple decubitus ulcers could be managed entirely at home with IV antibiotics and wound care after an initial assessment in the Emergency Department.

Conclusions

Children with medical complexity represent a small percentage of children overall but account for a disproportionate percentage of pediatric medical expenditures. CMC and their families have specific needs related to the chronicity of their medical and developmental conditions which require expertise in management, and a broad range of needs for subspecialty care, therapies and ancillary services. What's more, their care is time consuming and, often, management of their non-acute needs is poorly reimbursed.

Clearly there is indication for developing financially sound systems of care which address both the need for care coordination and expertise in chronic medical conditions. From ambulatory models of Medical Home and case management to inpatient models of complex specialty services and consultation, and the spectrum of alternatives outlined above, novel programs are cropping up quickly at the national level. These programs are designed to provide comprehensive and coordinated care, to ensure communication between all providers and caregivers, to ease of patient access

to all needed elements of care, and to proactively address anticipated problems and functional limitations. There is no single idealized model of care for all CMC. Instead, elements of the models discussed can be applied to a given system's resources, personnel, patient needs, and population to construct a model that will best fit a given situation.

As these models emerge, there is opportunity for increasing discussion about standardization of care and creating curricula for medical education for physicians, nurses and trainees alike. With enhanced models of care delivery the possibility for improving quality of life for CMC as well as the providers who care for them can be a reality.

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