

Models of Care Delivery for Children With Medical Complexity

Elisabeth Pordes, MD, MPH,^a John Gordon, MD,^a Lee M. Sanders, MD, MPH,^b Eyal Cohen, MD, MSc^c

abstract Children with medical complexity (CMC) are a subset of children and youth with special health care needs with high resource use and health care costs. Novel care delivery models in which care coordination and other services to CMC are provided are a focus of national and local health care and policy initiatives. Current models of care for CMC can be grouped into 3 main categories: (1) primary care–centered models, (2) consultative- or comanagement-centered models, and (3) episode-based models. Each model has unique advantages and disadvantages. Evaluations of these models have demonstrated positive outcomes, but most studies have limited generalizability for broader populations of CMC. A lack of standardized outcomes and population definitions for CMC hinders assessment of the comparative effectiveness of different models of care and identification of which components of the models lead to positive outcomes. Ongoing challenges include inadequate support for family caregivers and threats to the sustainability of models of care. Collaboration among key stakeholders (patients, families, providers, payers, and policy makers) is needed to address the gaps in care and create best practice guidelines to ensure the delivery of high-value care for CMC.

^aChildren's Hospital of Wisconsin and Medical College of Wisconsin, Milwaukee, Wisconsin; ^bLucile Packard Children's Hospital and Center for Policy, Outcomes and Prevention (CPOP), Stanford University, Palo Alto, California; and ^cDepartment of Pediatrics, The Hospital for Sick Children and Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, Ontario, Canada

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Address correspondence to Eyal Cohen, MD, MSc, Department of Pediatrics, The Hospital for Sick Children, 555 University Ave, Toronto, ON M5G 1X8, Canada. E-mail: eyal.cohen@sickkids.ca

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TABLE 1 Examples of Services Provided by Models of Care for CMC

Medical Comanagement	Care Coordination	Family and/or Caregiver Support
Facilitate multidisciplinary care team discussions and disease management	Coordinate procedures, appointments, and tests to reduce redundancy or multiple sedations	Provide key point person who is familiar with a child's "journey" and is the go-to for the family
Assist with management of polypharmacy with emphasis on recognition of interactions and side effects	Follow-up phone calls and check-ins to answer questions and ensure parental understanding of discharge instructions	Facilitate goals of care discussions
On-call services with providers familiar with patients	Create shared care plans and emergency plans	Work with caregivers to ensure their own health and emotional needs are being addressed
Triage acute medical issues and provide guidance to referring facilities, emergency departments, and home care agencies	Communicate with schools regarding medical and education care plans	Assist families with insurance issues and financial resources
Support providers unfamiliar with patient's medical history		Connect families in efforts to create community and peer support systems
		Advocate on multiple levels for expanded in-home services and parental support systems

Children with medical complexity (CMC) are a subset of children and youth with special health care needs who are characterized by multiple chronic conditions, high health care needs and costs, frequent technology dependence, neurologic impairment, and functional limitations.¹ Conventional health care systems are not structured to adequately address the high and costly needs of the CMC population and their families.² Many needs (eg, care coordination, medication management, respite, and mental health) go unmet,^{3,4} and families are often left shouldering the responsibility of providing medical and/or nursing care and care coordination for CMC.^{5,6} Because of these factors, improvements in care delivery for CMC have become a major focus in pediatric care delivery systems. There has been a rapid proliferation in the creation of new models of care as evidence emerges that they can be cost effective.⁷⁻⁹

In this article, we explore current models of care in which the multifaceted needs of CMC and their families are addressed in efforts to help guide leaders of health care systems or other stakeholders interested in improving care of CMC. We present advantages, disadvantages, and emerging

solutions for different models; explore current evaluative literature; and address some of the gaps in care.

GENERAL PRINCIPLES FOR MODELS OF CARE FOR CMC

In most existing models of care for CMC, enhanced care coordination services are provided together with other supports. "Care coordination" in this context is a set of services that are provided by a defined team and are patient- and family-centered, assessment-driven, and designed to address the goals and meet the needs of the patient and family.¹⁰ In enhanced care coordination, continuity, familiarity, accessibility, partnership, and early crisis recognition are emphasized. It has been suggested that in an ideal care delivery model for CMC, the creation of proactive plans based on family and children goals is emphasized, the timely treatment of urgent acute health issues is enabled, multidisciplinary shared decision-making is facilitated, and a provider familiar with the child and/or family is involved to address comprehensive needs.¹¹ Enhanced care coordination services offered within existing models of care are highlighted in Table 1.

We have divided models into 3 broad categories: (1) primary

care-centered (PCC) models, (2) consultative- or comanagement-centered (CC) models, and (3) episode-based (EB) models. The characteristics, advantages, and disadvantages of each model are described below and summarized in Table 2.

Within each of the main model categories, further variety exists. Programs differ in their location, payment systems, target populations, care team staff, and services offered. Variations are due to differences in local needs, the expertise of founding members, the preferences of stakeholders, (eg, patients, families, primary care practitioners, and hospitals), and available financial and/or institutional support. In some programs, both primary care and consultative services are provided. The wide heterogeneity of models is a reflection of the current lack of consensus on what constitutes the best practices within the emerging field of pediatric complex care and for the diverse needs of the CMC population.

In this article, we focus on models in which direct medical care for CMC is provided. Distinct from these models is a standalone care-manager model in which a nurse, a social worker, or a community navigator works as a representative of a hospital, county, government and/or nonprofit

TABLE 2 Characteristics of the 3 Categories of Models of Care for CMC

Model	POC		CC		EB	
Variation	Location		Scope of Practice		Inpatient Service	Acuity of Care
Examples	Community-Based ^{12,13}	Tertiary Care Center ^{7,14}	Ambulatory ^{15,16}	Combined inpatient and Ambulatory ^{8,15,17}	Consult Team ¹⁸	Other Facility ¹⁹
Services commonly provided in addition to care coordination	Preventive care		Consultation for management of rare or multiple diseases ^a		Teaching and/or education regarding new medical equipment or technology	
Advantages ^b	<p>Anticipatory guidance</p> <p>Sick care (eg, intercurrent illness management)</p> <p>Ease of travel for families</p> <p>Awareness of local culture, values, and resources</p> <p>Covisits with siblings</p> <p>Previously established relationships</p> <p>All children initially eligible</p> <p>May facilitate primary care transitions and/or health care for parents if integrated with adult health care system</p> <p>Ability to match services provided with needs of patients</p>	<p>Occasional sick visits, ED consultation</p> <p>Access point for children who live a distance from the tertiary care center</p> <p>Dedicated provider on-call services</p> <p>Connection to tertiary-based services</p> <p>Cohorting of patients allows for streamlining processes and development of trained workforce</p> <p>Provider familiarity and comfort with complex diseases and/or creation of specialized “complex-ology” workforce</p> <p>Enables children to be managed across multiple hospital care settings</p>	<p>Around-the-clock bedside care</p> <p>Acute care medical management</p> <p>Ability to assess and impact treatment and/or clinical status at sickest time</p> <p>Burden of care provision not on family</p> <p>Focus on transitions: for example, the creation of discharge standardization to limit gaps in care and aim to reduce readmissions</p> <p>Workforce that is familiar with caring for CMC</p>			
Disadvantages	<p>Insufficient infrastructure and personnel for care coordination</p> <p>Time constraint</p> <p>Obstacles to sharing medical records across different systems</p> <p>Lack of skill set</p>	<p>Enrollment criteria may result in missing children with unmet needs</p> <p>Finite tertiary center financial, structural, and staff resources</p> <p>Service delivery may be more expensive</p> <p>Risk of diffusion of responsibility, given unclear patient ownership</p> <p>Lack of integration with community-based services</p> <p>Cross-organizational collaboration</p>	<p>Services often provided at a distance from family</p> <p>Risk of poor continuity of care between care locations</p> <p>Inconsistent care teams</p>			
Emerging facilitators	<p>CMC may receive majority of care elsewhere</p> <p>Multipractice partnerships</p> <p>Extended office hours and practice times</p> <p>Use of alternate technology modes of communication, such as e-mail, telemedicine, and patient portals</p> <p>Negotiations with payers for reimbursement for non-face-to-face and non-MD coordination services</p> <p>Multilevel care teams</p> <p>Creation of standardized definitions and outcome metrics to promote further model evaluation</p>				<p>Transitional care facilities</p> <p>Standards of care for chronic issues and discharges</p>	

TABLE 2 Continued

Model	PCC		CC		EB	
	Location	Scope of Practice	Inpatient Service	Acuity of Care	Consult Team ¹⁸	Other Facility ¹⁹
Examples	Community-Based ^{12,13} Tertiary Care Center ^{7,14}	Ambulatory ^{15,16} Combined Inpatient and Ambulatory ^{8,15,17}	Inpatient Service	Acuity of Care	Consult Team ¹⁸	Other Facility ¹⁹
Ideal patient population	Parent-to-parent support, interactions, and advisory boards For community-based practices; minimal to moderate complexity with episodic specialty consultation Local patients, integrated health care system	Frequent tertiary care resource use Disease-specific disorders, rare diseases or treatments, high medical technology use Patients who live a distance from tertiary care center	Frequent or prolonged hospitalizations and readmissions			

ED, emergency department; MD, medical doctor.

^a Some hospital-based consultative services also offer short-term primary care services as medical and care coordination needs are stabilized.

^b Several advantages for consultative services because of hospital access also extend to the tertiary care-based primary care.

agency, or insurance company to provide care coordination services.^{2,20,21} This type of care-manager model is common in the inpatient setting and is increasingly used in the outpatient setting.^{21,22} The efficacy of agency-based care managers improves when they are integrated into primary care practices.²³ This standalone care-manager model has the advantage of the delegation of nonclinical, often time-intensive duties to staff who ideally have increased community insight, and connections are often less costly to the health care system than advanced medical providers.²⁰ A few evaluations of insurance care-manager programs have revealed cost savings and improved disease-specific outcomes for children with chronic conditions^{24,25}; however, there remains little evaluative literature on this model overall or specifically for CMC.

PCC MODELS OF CARE

PCC models of care delivery for CMC encompass the concept of the American Academy of Pediatrics' medical home. These models may be community- or tertiary care-based, with emphasis on the delivery of services that are continuous, coordinated, compassionate, and culturally appropriate through a primary care center.²⁶ Multiple health, policy, and nonprofit organizations champion care coordination through PCC models.^{26,27}

Advantages of PCC Models of Care

PCC models build on the strength of long-standing relationships between primary care practices, families, and their local communities.²⁰ Because relationships between primary care teams and families may begin before the manifestations of a child's illness, providers within

PCC models are uniquely positioned to provide varying services as the needs of CMC and their families evolve. Additional advantages include the proximity to a patient's home, an understanding of the local context and cultures, an ability to provide care for other family members, and functioning as a single location for comprehensive general and/or primary care and care coordination services.²⁰

Disadvantages of PCC Models of Care

Although often recommended as the ideal model, addressing the needs of this diverse and complex population presents challenges for primary care physicians (PCPs).²⁸ In a recent survey from the American Academy of Pediatrics of over 500 pediatricians, 40% agreed or strongly agreed that the medical home for children with complex or rare conditions should be located within a tertiary care specialty clinic.²⁹ Barriers to providing care noted by PCPs include high costs, poor reimbursement, the time needed to provide services, a lack of communication and coordination tools, inadequate knowledge to address complex acute illness, and limited personnel and community resources.^{28,29} Providers within PCC models struggle with the delivery of comprehensive care in siloed health care systems. Fragmentation of care is a particular risk because many CMC rely on inpatient and subspecialty care for treatment and do not attend routine PCP follow-up.³⁰ The lack of patient contact compounded by poor communication across health care settings^{6,31} (including incompatibility of electronic medical records) presents a major obstacle for comprehensive care delivery within PCC models.

Emerging Solutions to Improve PCC Models of Care

New strategies to improve care delivery include the creation of

“enhanced” PCC complex care programs dedicated to serving CMC and, often, their siblings. In many of these programs, resources and staff are centralized within a tertiary care center.^{7,14,15,32} These programs are often based around a team model and staffed with providers from multiple disciplines, such as subspecialty physicians, general pediatricians, nurses, care coordinators, social workers, and dietitians. For community models with smaller panels of CMC patients, collaboration among practices, standardized coordination protocols, and shared resources improve care delivery.¹² Other interventions to provide comprehensive care include nonphysician care coordinators,³² telemedicine,³³ e-mail, external case managers,² increased accessibility to a primary provider,⁷ longer and more frequent clinic appointments,¹⁴ parental advisory groups,¹² and standardized care coordination quality improvement tools.¹³

CC MODELS OF CARE

CC models are defined here as models in which providers in subspecialty programs, or more general complex care programs at tertiary care centers, deliver care coordination services, often in partnership with PCPs. Distinct from PCC models, CC models are generally not a patient's first entry point for access to health care and often do not include routine child care. Analogous to those of many palliative care programs, the efforts of CC models are commonly focused on care coordination services, goal-directed comanagement of medical issues, and acting as a bridge between the tertiary care center and the community.^{8,17,34} In consultative models, recommendations regarding specific questions are typically

provided, whereas comanagement models are engaged over a longer period of time, taking a more or less active role as dictated by needs. Long-established examples of the CC model are subspecialty programs structured around a single disease or type of technology assistance. Nondisease-specific models often staffed by generalists and located within tertiary care centers are becoming more prevalent.

Advantages of CC Models of Care

Advantages stem from being part of a hospital system and the colocation of patients, resources, and care teams.²⁰ Providers in CC models are well positioned to care for CMC who have multiple complex chronic conditions, frequent hospitalizations, frequent subspecialties visits, rare diseases, and high levels of technology assistance. CC models may be especially important for families who need to access tertiary care services but live a distance away from the center or lack access to a PCP within the network. With a cohort of complex patients, providers in CC models are well positioned to improve efficiency, decrease cost, and negotiate with payers.

Disadvantages of CC Models of Care

The consolidation of resources in 1 geographic center presents challenges. Because many children do not live near tertiary care centers or subspecialty care,³⁵ the centralization of resources and expertise in tertiary care centers leads to difficulties in the remote management of acute illness and communication with local support services. Given poor reimbursement for the care coordination activities

at the core of the CC model, many programs rely on unstable and transient revenue sources such as extramural grants or hospital support. Funding constraints limit the capacity to care for all CMC within a system and drive many providers in CC models to rely on medical-based inclusion and exclusion criteria for enrollment. Such criteria inherently lead to the exclusion of some children (eg, those with primary mental health or social complexity) who also have many unmet needs and a potential for high health care use. Maintaining a steady workforce in a program focused solely on CMC can be a struggle because the work is time-consuming and emotionally challenging.

Emerging Solutions to Improve CC Models of Care

Those working within CC programs have developed solutions to address the challenges associated with the delivery of comanagement rather than primary care services when patients are being managed by multiple providers and/or teams. Risks of unclear patient ownership and diffusion of responsibility can be mitigated by personal and timely communication among care providers and the creation of accessible care plans in which provider- and family-specific responsibilities are assigned. Other tools to enhance communication and accessibility include home visits, telemedicine, e-mail, shared health care portals, and on-call services available for both families and other providers.³⁴ In 1 CC program, face-to-face services are delivered within a patient's local community by holding weekly comanagement care coordination clinics staffed by a tertiary-care nurse practitioner and a community pediatrician.¹⁷ Partially in response to scarce resources, the providers within some CC models use

a multilayered care team approach, matching skill sets with tasks, with nonphysicians providing many of the care coordination services, including direct communication between care teams.⁸

EB MODELS OF CARE

The common element of EB models are time- or location-limited interventions focused on providing medical management and care coordination for a specific illness episode or transitional period. During a discrete care episode, a child is often acutely or critically ill, and families are often most stressed. Examples of EB models include an inpatient service in which a small care team accustomed to treating complex conditions focuses on care of a targeted group of CMC,^{36,37} transitional care homes where children live between hospitalization and home while their parents are educated on new medical equipment, and inpatient rehabilitation facilities.

Advantages to EB Models of Care

Advantages stem from the ability of trained staff to deliver around-the-clock care when a child and family are most vulnerable. During hospitalizations, parents of CMC report a sense that they are being left alone to care for their children,³⁸ express fear for their children, have additional worries about absence from their other children and days missed from work, and face tough decisions about end-of-life-care. A care team familiar with the family and child, included in many EB models, may help mitigate some of these negative feelings.³⁸ Inpatient CMC services are designed to focus on the chronic as well as acute needs of CMC during inpatient stays by

improving care coordination and the transition into outpatient and/or community care.²⁰ The effects of new medications, treatments, and medical technologies are closely monitored in a given time period within the context of an EB model of care, which is of particular benefit for CMC, given the risk of medication interactions and unwanted side effects.

Disadvantages to EB Models of Care

Disadvantages relate to the location and episodic nature of EB models. There is a risk that chronic needs are not addressed because more acute issues are prioritized. Increased hand-offs that are intrinsic to providing 24/7 care and inadequate communication with ambulatory care teams (eg, home nurses, schools, PCPs, outpatient subspecialists) place CMC at high risk for medical errors and gaps in care. Further discontinuity of care develops when the care coordination services a child receives during a specific episode of care are discontinued on discharge. There is limited ability to prevent illness exacerbation before hospitalization in these current EB models.

Emerging Solutions to Improve EB Models of Care

There is growing recognition among inpatient providers that to improve care for CMC, hospital staff may need to be involved in a child's care beyond the acute hospitalization.³⁶ Those working within a few current complex care programs aim to bridge the gap between inpatient and outpatient care by providing services in both locations.⁸ Some programs have dedicated inpatient teams with small staffing numbers to provide continuity, whereas others have the outpatient providers rotate on and off inpatient service or

provide consultations to address readmissions or prolonged stays. Structured hand-off tools³⁹ and CMC-specific discharge protocols⁴⁰ may improve the transition to ambulatory care. Transitional facilities, including rehabilitation institutions, also represent an emerging strategy to improve continuity as a child moves between care locations. These facilities are used when an acute illness is stabilized but a child cannot return to the community for a variety of reasons (eg, a need for parental education, a need for home nursing, or to finish a treatment course). CMC, and sometimes their families, can reside for a period of time at these locations while families acquire the skills to use technology or equipment, children receive developmental therapies, and care coordination needs are addressed.¹⁹

CMC MODELS OF CARE EVALUATIVE RESEARCH

Regardless of the model, the authors of the majority of published evaluations of care delivery for CMC have shown an improvement in outcomes such as parental satisfaction, length of stay, unmet needs, and health care cost.¹⁵ However, these studies have several limitations, including inadequate control groups; small sample sizes; single-center, mostly hospital-based designs; and heterogeneous study populations. The authors of 1 of the few randomized control studies on model effectiveness, at a single tertiary care center in Houston, Texas, reported reduced costs and serious illness.⁷ The results of this study reveal the positive impact of a comprehensive care program for CMC; however, these outcomes may have been due to program- and population-specific factors that may not generalize to broader populations of CMC or to other settings.

TABLE 3 Characteristics of Successful Adult Complex Care Management Programs and Unique Issues Relevant for CMC

Characteristics of Successful Adult Programs ⁴¹	Unique Issues Relevant for CMC
Customized approach based on local contexts and case loads	Subspecialized care tends to be centralized at tertiary care centers ³⁵
The use of a qualitative and quantitative method of identifying patients for enrollment	Smaller numbers of children with rare and unusual diseases make disease-based identification difficult; identifying CMC without reference to a particular disease is complicated by a lack of an agreed-on definition of medical complexity
Focus on care coordination	A large amount of care is provided in nontraditional care settings, such as in the home or the school
Emphasis on building trusting relationships with patients and community providers	Parents are often primary caregivers and have unique relationships and/or needs
Care team composition and intervention matched to patient needs	The breadth of rare diseases and unusual treatments make it difficult to simply scale up services as one would for common complex conditions such as congestive heart disease and its complications
Staff and providers receive specialized training	The nascent field of pediatric complex care has few norms or standard proficiencies
New technology is used to enhance services	Technologies must be accessible to multiple caregivers, including home health providers and families

To our knowledge, there is currently no comparative research on different models of care for CMC. In the adult complex care literature, the authors of a qualitative comparison of 18 successful adult complex care management programs identified 7 characteristics of highly effective programs.⁴¹ These foundational components with some pediatric adaptations are summarized in Table 3. The lack of a well-defined target population and standard outcomes for CMC make comparative investigations challenging. Even for relatively common CMC populations (eg, children with cerebral palsy who use a feeding tube) there are no well-defined outcome metrics. Disease-specific physiologic metrics (eg, hemoglobin A1c) are not applicable for CMC whose numbers and disease variety make similar population-based metrics impossible. Other common metrics, such as readmission rates, may not be reflective of the quality of care for CMC who have variable and

often unpredictable disease courses and whose families may prefer to risk readmission so that their children can partake in specific events at home that contribute to their quality of life.

There is work on the national level to create evidence-based practice guidelines for models of care for CMC. The Centers for Medicare and Medicaid Services has awarded 6 Health Care Innovation Awards to a variety of models of care for CMC to determine scalable best practices in care delivery for CMC and a new payment structure.⁴² In addition, centers of excellence funded by the Centers for Medicare and Medicaid Services and the Agency for Healthcare Research Quality have focused on creating standardized outcomes, mainly in the form of validated surveys such as Quality of Care Measures for Children with Complex Needs.⁴³ The results of such surveys will help us better define what the child and family see as “value,” and these surveys are necessary next steps in comparative

evaluation and for identifying which features of models of care for CMC are most impactful.

GAPS IN CURRENT MODELS OF CARE

Despite ongoing efforts, several gaps in care are common across models. We highlight the following gaps: (1) the poor integration of medical and community services, especially regarding addressing social determinants of health; (2) a limited focus on mental and/or behavioral health care; (3) difficulties achieving smooth transitions to adult care; (4) a lack of sustainability strategies; and (5) inadequate support for family caregivers.

Poor Integration of Medical and Community Services

The integration of information and services from a variety of sources (eg, schools, recreation, the home, social services, or medical services) is important to families^{44,45} but difficult to achieve through the current, mostly medically based, care models. Disparities in care for low-income, minority, and non-English-speaking families of children with special health care needs exist,^{46–48} and simply providing access to a family-centered source of care does not eliminate these disparities.⁴⁹ Relatively little is known about the most effective way to combat the impact of social disparities on the health of CMC. The integration of social workers in care teams and the development of novel technologies, such as a platform for communication between social and medical services,⁵⁰ may help bridge the gap between medical and community services in efforts to create the ideal “patient-centered medical neighborhood.”⁵¹

Limited Focus on Mental and/or Behavioral Health Care

The rate of unmet mental health needs for CMC is 3 times that of

children with special health care needs without complexity.³ Parents of CMC associate poor mental health with poor quality of life for their children.⁵² Despite the fact that care coordination services for children with disabilities improves access to mental health treatment,^{53,54} few care delivery systems target CMC with primary mental health issues, and few models integrate mental health services. Ideally, the existing care coordination and multidisciplinary structure within models of care for CMC could be used to adapt tools used in primary care (eg, quick access to telephone pediatric psychiatrist consultations, colocation or in-house integration with behavioral health specialists, and school-based health care services)^{55–57} to address the mental health needs of CMC.

Difficulties Achieving Smooth Transitions to Adult Care

There is little support for families, patients, and providers, and there are few standards of practice for transitioning CMC from pediatric to adult health care. Difficulties associated with the transition to adult care noted by families include finding an adult provider who is knowledgeable or familiar with their child’s disease or disability, adjusting to the adult style of medicine, changing from a focus on the family to a focus on the patient, and leaving long-standing trusting relationships with current pediatric doctors.⁵⁸ Many pediatric providers, especially subspecialists, are reluctant to transition patients from pediatric care to an adult mode of care.⁵⁹ Few adult care providers are appropriately trained and/or interested in caring for complex childhood-onset disorders. Complex care programs may become the default providers for young adults with complexity, inadvertently widening the gap between pediatric and adult care services. One proposed transition

model revolves around collaboration among pediatric subspecialists, adult medicine specialists, and adult PCPs to address health issues that arise with aging.⁶⁰ Ideal models of care for CMC include partnerships with adult medical providers and care teams to ensure the continuation of enhanced care coordination services and a structure for care transition.

Lack of Sustainability Strategies

High-quality care delivery for CMC is time-consuming and poorly reimbursed. Health care financing systems are anchored in the care of adults, especially those with costly and modifiable chronic conditions, with little attention to the special requirements of CMC. Remuneration is based largely on fees for face-to-face services and procedures. Consequently, the time spent on non-face-to-face care coordination activities, which are the backbone of most models of care for CMC, remains under- or unfunded. Recognizing this, some successful complex care programs are initially focused on a small target population with high resource use to curb costs and garner institutional support. In a few models of care, state Medicaid amendments for reimbursement are used. However, such amendments are rare, time-consuming, and difficult to achieve.⁶¹ Recruiting and retaining personnel is a challenge for many programs. Supporting the mental health of personnel who constantly care for chronically ill children who have unknown disease trajectories and high rates of early mortality is essential to prevent burnout.

Inadequate Support for Family Caregivers

CMC rely heavily on informal and unpaid caregiving by families. When compared with adults with complexity, CMC are less likely to receive home care or respite care.² The reliance on nonformal

caregiving for children is likely due to the combination of family and provider preference for in-home care, increasing pressures to reduce length of stay and the scarcity of a skilled in-home professional workforce.^{62,63} The effects on caregivers of providing these intensive in-home care and coordination services are significant. Despite efforts to provide support, a child's enrollment in a model of care for CMC does not always improve a parent's low quality of life or overall health.^{64,65} Parents of CMC report increased stress, decreased sleep, lost revenue, unemployment, and resentment over having their time and energy absorbed by care coordination, administration, and advocacy activities.^{5,66,67} Much of this work by families goes unnoticed, underappreciated, and unpaid.^{66,68} As children spend less time in the hospital, there is likely a shunting of costs from the medical system to families. Families forgo thousands of dollars in earnings to provide medical care services for their children, and replacement of

family-provided health care by a home health aide would cost \$6400 per child with special health care needs.⁶⁹ An ideal care delivery system for CMC would partner with families to ease their financial, time, and emotional burden and provide caregiver support systems, such as increased in-home care, respite facilities, financial resources, and access to high-quality adult mental and physical health care.

CONCLUSIONS

We have described various categories of models of care for CMC, each with specific advantages and disadvantages, in which the aim is to improve quality of care and reduce cost for CMC. Given the importance of context (location, family resources, primary care provider preference, and access to tertiary care) on the delivery of care to families and children, there cannot be a "1-size-fits-all" model of care. Substantial challenges for current models exist, including financial sustainability and mechanisms to best support family

caregivers. Ongoing integration of research and advocacy to develop standardized outcome metrics, enhance existing models of care, and evaluate care delivery systems is essential to ensure the delivery of high-value care for CMC.

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ABBREVIATIONS

CMC: children with medical complexity
EB: episode based
CC: consultative or comanagement centered
PCC: primary care centered
PCP: primary care physician

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