

# Children With Medical Complexity: The 10-Year Experience of a Single Center

Nancy A. Murphy, MD,<sup>a</sup> Justin Alvey, MD,<sup>a</sup> Karen J. Valentine, MStat,<sup>b,c</sup> Kilby Mann, MD,<sup>a</sup> Jacob Wilkes, MS,<sup>b</sup> Edward B. Clark, MD<sup>a</sup>

Children with medical complexity (CMC) have chronic, multisystem health conditions, substantial health care needs, major functional limitations, and high resource use. They represent <1% of US children yet account for more than one-third of total pediatric health care costs. Health care systems designed for typical children do not meet the unique needs of CMC. In this special article, we describe the experience of our Comprehensive Care Program for CMC in a pediatric tertiary care center, from its launch in 2007 to its present model. We review the literature, describe our collective lessons learned, and offer suggestions for future directions.

## ABSTRACT

[www.hospitalpediatrics.org](http://www.hospitalpediatrics.org)

DOI:<https://doi.org/10.1542/hpeds.2020-0085>

Copyright © 2020 by the American Academy of Pediatrics

Address Correspondence to Nancy A. Murphy, MD, Department of Pediatrics, School of Medicine, University of Utah, 81 N Mario Capecchi Dr, Salt Lake City, UT 84113. E-mail: [nancy.murphy@hsc.utah.edu](mailto:nancy.murphy@hsc.utah.edu)

HOSPITAL PEDIATRICS (ISSN Numbers: Print, 2154-1663; Online, 2154-1671).

**FINANCIAL DISCLOSURE:** The authors have indicated they have no financial relationships relevant to this article to disclose.

**FUNDING:** No external funding.

**POTENTIAL CONFLICT OF INTEREST:** The authors have indicated they have no potential conflicts of interest to disclose.

Dr Murphy conceptualized and designed the study, drafted the initial manuscript, and reviewed and revised the manuscript; Ms Valentine and Mr Wilkes performed all statistical analyses, guided the interpretation of data, and reviewed and revised the manuscript; Drs Mann and Alvey reviewed and revised the manuscript; Dr Clark conceptualized and designed the study and revised the manuscript; and all the authors participated in the concept and design, analysis and interpretation of data, and drafting or revising of the manuscript and have approved the manuscript as submitted.

<sup>a</sup>Department of Pediatrics, School of Medicine, University of Utah, Salt Lake City, Utah; <sup>b</sup>Intermountain Primary Children's Hospital, Intermountain Healthcare, Salt Lake City, Utah; and <sup>c</sup>Healthcare Delivery Institute, Intermountain Healthcare, Murray, Utah

Children with medical complexity (CMC) have significant chronic health conditions that involve multiple organ systems, substantial health service needs, major functional limitations, and high health resource use.<sup>1</sup> Although CMC comprise <1% of all US children, they account for an estimated 30% of all pediatric health care costs,<sup>2</sup> 56% of hospitalized patients, 82% of hospital days, and 86% of hospital charges in US children's hospitals.<sup>3</sup> In the past decade, hospitalizations for children with chronic conditions have increased nationally by 33%. Medical homes, hospital-based programs, home care, telehealth, and disease-specific specialty clinics have been implemented, with the goal of increasing health care value for CMC.<sup>4</sup> How do we measure our progress? We aim to quantify health care value for CMC, measure health outcomes longitudinally, and statistically summarize outcomes with aggregated administrative data. At the same time, it is important to couple our quantitative outcomes with rich, qualitative descriptions of our collective experiences. We will use a clear understanding of best practices to inform and strengthen essential inpatient and outpatient pediatric collaborations around the care of CMC and their families across the continuum.

In this article, we describe the experience of one pediatric complex care program, from its launch in 2007 to its present model. Our program spans the continuum of care, including inpatient, postacute, and outpatient care, as part of a large academic pediatric health care system. We have a resilient team of passionate providers, fully engaged families, and strong collaborations with the larger pediatric generalist-subspecialist communities. With more than a decade of experience, we acknowledge that we are just at the beginning of this journey and offer qualitative and quantitative descriptions of our single center's experience to characterize the heart of this work. We review the literature, describe our collective lessons learned, and offer suggestions for future directions.

## THE EVOLUTION OF OUR PEDIATRIC COMPLEX CARE PROGRAM

### The Beginning: Special Care Program

To develop a business plan for the start-up of a pediatric complex care program in our academic health center, we queried the fiscal year 2006 administrative data of one Intermountain West–based health plan to broadly characterize the 200 most costly children in that system. This small pediatric sample accounted for a total cost of \$17.5 million. On the basis of a review of categories of *International Classification of Diseases, Ninth Revision* codes, most of these children had chronic conditions. The average cost per child per year was \$53 686 and, for a child with a neurodevelopmental disability, \$65 216. Inpatient medical and surgical claims accounted for nearly 50% of total costs (>\$8 million). In response, our academic health center developed a program for CMC in 2007, with input from an interdisciplinary advisory board and in collaboration with a tertiary care children's hospital in an integrated health care system. Our mission, sparked by the Institute for Healthcare Improvement's Triple Aim framework in 2007, was to improve the patient experience, improve the health of a population of CMC, and reduce per capita health care costs.<sup>5</sup> With support from the academic health center's department of pediatrics and its affiliated children's hospital, the Special Care Program opened its doors in 2007, with a consultative model of comanagement for CMC in collaboration with pediatric generalists, subspecialists, and hospitalists. The institutional review board of the integrated health care system approved the use of administrative data for research purposes.

To demonstrate clinical need and program feasibility, the Special Care Program was piloted initially by one physician (pediatric physical medicine and rehabilitation [PM&R]), who served as its sole provider and medical director. All referred children were seen without screening for participant criteria, and the service grew exponentially. The program attracted children with significant and multifaceted disabilities,

often with tracheostomy and ventilator (TV) dependencies. We quickly expanded our pilot program by recruiting an advanced practice provider and otherwise adhered to the administrative request that we use existing resources. Social workers, nurse care managers, dietitians, and child life specialists contributed to our program on a case-by-case basis, carving time out of their usual responsibilities to share their expertise. Requests for inpatient consultations increased. The response from all stakeholders was positive. This pilot phase successfully revealed the feasibility, need, and interest in formalizing a program for CMC; it brought opportunities to build capacity, define the program's scope, and implement novel staffing and financing models.

### The Present Model: Comprehensive Care Program

In 2010, the pilot program of the Special Care Program was formalized and renamed the Comprehensive Care Program (CCP). We serve infants, children, and young adults with high medical complexity ( $\geq 3$  body systems affected), high medical fragility (frequent and/or prolonged hospitalizations), technology dependencies (feeding tubes, tracheostomies, ventilators, intrathecal baclofen infusion systems, and others), and high resource needs. Although not a criterion, many of our CMC and families also have high psychosocial complexity. CMC enter our program via physician, self, or community-agency referral. The CCP is a consultative model based on comanagement with primary care providers, hospitalists, and subspecialists. CMC and families are seen in 60-minute outpatient visits. Those with TV dependencies are seen in the CCP's interdisciplinary TV program. The CCP providers partner with each child's family and health care team to establish, update, and implement goal-directed shared plans. We practice principles of rehabilitation medicine and the *International Classification of Functioning, Disability and Health* to engage with families around goals of care.<sup>6,7</sup> Non–face-to-face care via phone or telehealth and urgent clinic visits are provided as alternatives to emergency

department (ED) visits. Families have continuous access to established and experienced providers. Families and providers consider prognosis, goals of care, and advanced directives around each medical decision point.<sup>8</sup> A CCP registry supports continuous care and communication between hospital and community settings.

### Pediatric Complex Care Providers

The CCP has included pediatric physiatrists, palliative care physicians, pediatric hospitalists, and general pediatricians. On-call coverage is provided 24 hours a day, 7 days a week. Integral to the program are advanced practice providers (physicians assistants and nurse practitioners) and complex care coordinators (registered nurses and medical assistants). Patient-to-provider ratios vary widely, reflecting provider turnover and varying degrees of medical complexity and fragility in a heterogeneous group of CMC. Turnover of physicians and, to a lesser degree, staff is a great challenge. Physicians have left our CCP to pursue related and more focused interests (palliative care, PM&R, and general pediatrics), often feeling that the complexity of this work weighs heavily on their shoulders, time invested between visits is uncompensated, and uncertainty can be uncomfortable. We diversify provider responsibilities to lighten the experience of this complex work. For example, pediatric PM&R physicians might work in general PM&R clinics or the inpatient rehabilitation unit, palliative care providers might rotate with their inpatient team, and pediatricians might work in general outpatient pediatric clinics with typically developing children. This blend of inpatient and outpatient work strengthens essential collaborations between CCP providers and hospitalists. Because CCP providers feel limited by the challenges of longitudinal documentation in electronic health records (EHRs) that are designed primarily for adult patients with acute conditions, we have ongoing quality improvement projects to optimize our use of the EHR. Overall, our CCP providers invest an unquantified amount of personal “heart and soul” into caring for CMC and their families. We seek to identify and cultivate factors that

promote provider resiliency and sustain our invaluable workforce.

Our CCP providers consistently partner with our hospitalist colleagues in care delivery. In our tertiary care center, pediatric hospitalists are the attending providers for CMC admitted to inpatient units, and the CCP providers consult, formally and informally, during their hospitalizations. This model has been strongly favored by providers and families, most significantly as discharge planning is underway. More recently, a growing emphasis on outpatient CCP productivity has decreased our availability to provide inpatient consultations. At a recent educational conference with pediatric residents and via physician surveys, we are encouraged to resume our inpatient consultations; this is a suggestion that we are fully committed to implementing.

### OUTCOMES

#### The Value of Comprehensive Care

We summarize the health care costs and use trends of our 10-year CCP experience with a 6-month pre-post design. Because CMC receive care in our system as well as others, move from one health plan to another, and enter and leave our program at random intervals, our longitudinal data are discontinuous. Moreover, outcomes tracking is disrupted by the dynamic nature of health care delivery; in our setting, we implemented a new EHR in 2017 and experienced turnover of physician and advanced practice providers in 2018. Lastly, our CCP's health outcomes and use and cost data are likely influenced by the progressive rather than static nature of the pediatric chronic conditions that many of the CMC in CCP experience. These, and other factors, likely influence our outcomes in ways that are not accounted for in these descriptive analyses. We acknowledge these limitations, and share our story here.

We describe a sample of CMC in CCP who were  $\geq 2$  years of age on their first CCP visit and had  $\geq 2$  CCP visits, to avoid the influence of high historical inpatient and NICU costs. CMC in our representative sample of CCP participants ( $n = 507$ ) had a median age of 8 years; 45% were girls and

14% were enrolled in the TV program. By using Feudtner's complex chronic condition (CCC) scores, assigning 1 point for each organ system involved within predefined diagnostic categories (possible scores of 0–10),<sup>9,10</sup> the median CCC score was 4 (Table 1). Most (73%) of the children had neurologic and/or neuromuscular disorders, 60% had device dependencies, 50% had gastrointestinal conditions, and 50% had congenital conditions. During this 10-year period, 10% of the CMC in our program died. As expected, CMC with TV dependencies were the highest users of hospital resources in our sample. Among the CMC with hospital visits ( $n = 318$ ), we observed a 15% decrease in ED visits, 67% increase in observation visits, 32% decrease in hospital admissions, 68% decrease in hospital lengths of stay (LOS), and 69% decrease in total hospital costs (average of \$34 000 per child) (Table 2). CMC with TV dependency demonstrated the most significant reductions in mean total LOS (10 days,  $P < .01$ ) and mean hospital costs (\$59 000,  $P < .001$ ) in our pre-post analysis. Although regression to the mean might skew these exact numbers, our providers and families attest to a positive trend in the avoidance of ED and hospital encounters. Subjectively, we readily see the impact.

#### Parent Perspectives

What is the experience of parents of CMC in our CCP? To understand, we surveyed parents in 2012 about their perceptions of the health and well-being of their CMC. They told us that, on average, their children had 1 week per month during which their physical health, mental health, sleep, and/or pain rendered them unable to play or attend school. Despite these challenges, nearly all (86%) perceived their child's quality of life (QoL) to be good to excellent.<sup>11</sup> In a separate survey, parents of CMC reported that their own health-related QoL was lower than that of other parents.<sup>12</sup> Lastly, we asked parents to think about their child's health care and rate their level of agreement or disagreement with the statement, “I receive exactly what I want and need, exactly when and how I want and need it.” Nearly all (89%) parents agreed or strongly agreed with this statement.<sup>11</sup> In summary, despite

**TABLE 1** Demographics of CMC in CCP

Outcome	n (%) or Range
Total CMC, <sup>a</sup> N	507
No hospital visits <sup>b</sup> , n (%)	189 (37)
≥1 hospital visit <sup>b</sup> , n (%)	318 (63)
Median age at first visit, y (range)	8.4 (2–34)
Female, n (%)	230 (45)
Non-Hispanic and/or white, n (%)	353 (70)
TV program, n (%)	73 (14)
Death, n (%)	52 (10.3)
CCC per CMC, median (range)	4 (0–10)
Neurologic and/or neuromuscular, n (%)	368 (73)
Cardiovascular, n (%)	178 (35)
Respiratory, n (%)	127 (25)
Gastrointestinal	253 (50)
Renal and/or urologic, n (%)	63 (12)
Hematologic and/or immunologic, n (%)	41 (8)
Metabolic, n (%)	123 (24)
Congenital and/or genetic, n (%)	256 (50)
Malignancy, n (%)	32 (6)
Prematurity and/or neonatal, n (%)	94 (19)
Device dependencies, n (%)	306 (60)
Transplant, n (%)	6 (1)

<sup>a</sup> CMC ≥2 y of age at first visit and ≥2 CCP visits.

<sup>b</sup> During 6-mo pre- and post-CCP enrollment.

high levels of medical complexity and many days of fair to poor health, parents tell us that their CMC's QoL is favorable, describe satisfaction with their child's health care overall, and prioritize the needs of their children over their own health and personal needs. The critical role of supporting the child-family dyad in the CCP cannot be overstated.

## THE CURRENT STATE OF PEDIATRIC COMPLEXITY CARE

### Measuring Outcomes and Value

Our CCP has been in existence for over a decade, with the overarching goal of providing better care for CMC at a lower cost, or in a word, adding value.<sup>13</sup> Yet how do we measure its value for this small,

unique pediatric population? CMC are not static; they have progressive neuromuscular and metabolic disorders, genetic conditions, severe cerebral palsy, and other life-limiting conditions for which the traditional value equation does not apply. Moreover, the use of matching cases and controls fails for this population of children, who are better defined by their differences than their similarities. Randomly assigning CMC to systems designed for their complex needs or to those for typically developing children puts health care providers at risk for moral injury, which Dean et al<sup>14</sup> describe as “the challenge of simultaneously knowing what care patients need but being unable to provide it due to constraints that are beyond our control”.<sup>14,15</sup>

Measuring value goes beyond summarizing costs, which may or may not regress to the mean. In fact, families of CMC and health care providers remind us that child health, family health, and the experience of care are the 3 priority outcomes for complexity programs and call us to measure what matters.<sup>16</sup>

CMC, by definition, have high resource needs. Right-sizing their care by reducing waste,<sup>17</sup> harm, and overuse can be done to improve outcomes, safety, and value.<sup>18,19</sup> Yet caution is needed to avoid limiting or denying care or shifting nonreimbursed costs of care from payers to providers and families.<sup>20</sup> For example, many CMC and their families depend on pediatric home care nursing. When home nursing shortages delay hospital discharges,<sup>21</sup> families who are eager to get their children home often experience increased out-of-pocket expenses as they informally hire their own staff or leave employment to be at home. Access to services varies considerably by payer, and it is our collective imperative to advocate for CMC in an era of spending reduction.<sup>22</sup> Similarly, stakeholders are compelled to consider the ethical constructs of risk, effectiveness, and fairness.<sup>23</sup> Health care systems are called to provide the right amount of care at the right time, balancing over and underuse of resources.

The greatest change in health care costs during our CCP experience was observed in the subpopulation of children with TV dependencies. Children with tracheostomies have a two- to threefold greater morbidity and mortality compared with adult patients, and parent caregiving responsibilities are tremendous.<sup>24</sup> Interdisciplinary ventilator care programs are used to offer education, family to family support, and comprehensive health care and are associated with reductions of >40% in hospital LOS<sup>25</sup> and 43% in tracheostomy-related adverse events.<sup>26</sup> TV programs are emerging nationally in tertiary care pediatric centers, with top priorities of outcomes and safety.<sup>27</sup> They are part of the high value proposition of pediatric complex care.

**TABLE 2** CCP 6-Month Pre-Post Outcomes (n = 318)

Outcome	Pre-CCP (6 mo)	CCP (6 mo)	Difference	Change, %
No. ED encounters	224	191	−33	−15
No. observation visits	63	105	42	67
No. admissions	367	248	−119	−32
Total inpatient LOS	3383 d	1077 d	−2305 d	−69
Total hospital cost	\$14 708 026	\$4 615 838	\$10 686 974	−69

## Models of Care

Populations of CMC are growing, as are models of pediatric complex care. Yet we still lack evidence-based, value-driven and sustainable systems of care for these children. Wide variations in models of care delivery reflect our national state of “status complexicus.”<sup>28</sup> Complex care programs include primary care,<sup>29,30</sup> consultative care,<sup>31,32</sup> and/or comanagement models.<sup>33</sup> Although each program is unique, the common outcome is substantial cost avoidance, primarily through reductions in hospital days. In our experience, it is the trusted and continuous relationships between parents and providers that drive outcomes. Responsive and accessible health care for CMC decreases the need for families to seek urgent and/or emergency care for their children. Parent-provider partnerships in goal-directed care allow for the differentiation of acute, reversible conditions from chronic, irreversible conditions in CMC, supporting the provision of care in the most appropriate setting.<sup>34</sup> Regardless of the model of pediatric complex care, a workforce focused on parent-provider relationships is at the foundation.

Our CCP is primarily an outpatient service for CMC. In response to stakeholder input, we plan to increase our presence as inpatient consultants. Our hospitalist colleagues value the longitudinal relationships of CCP providers and families of CMC in our system; they build on that foundation when guiding families in decisions around goals of care and criteria for discharge. Future directions include exploring best practices for models of care during hospitalizations, whether that be a separate hospitalist service for CMC or comanagement with complex care providers. Additionally, we encourage interested pediatric hospitalists to step into the CCP to further integrate care across the continuum.

## Sustaining Programs and Developing the Workforce

The sustainability of complex care programs for CMC is uncertain in fee-for-service payment models, which culminate in financial losses for providers and

financial gains for payers.<sup>35</sup> The provision of indirect care, attention to social determinants of health, and continuous collaborations among parents, generalists, and specialists is constrained in traditional models of compensation. In our experience, indirect care, which includes all interventions that support CMC and their families outside of traditional face-to-face visits (care coordination, chart reviews, informal conversations with physician colleagues, peer reviews with payers, school and homecare communications, and others), accounts for 67% of total care time.<sup>36</sup> Care coordination for CMC requires substantial investments of nonreimbursed time, with a median estimated cost ranging from \$145 to \$210 per CMC per month.<sup>37</sup> Sustainable complex care programs must be integrated in health care systems that focus on population health rather than use in a fee-for-service market.<sup>38</sup> At a population level, these programs are strongly patient centered, ethically and morally grounded, and fiscally responsible. Alternative payment models, including those based on payments for value and outcomes, population-based approaches, shared decision-making, and team-based care delivery are used to offer opportunities to improve care and reduce costs.<sup>2</sup> CMC are rare; by regionalizing their care in specialized centers where a sufficient volume of children with relatively rare conditions receive ambulatory and inpatient pediatric subspecialty care, outcomes and costs may be optimized.<sup>38</sup> The delivery of care for CMC requires a specific level of physician experience and expertise. CMC often have rare disorders for which there are not well-defined care standards. It is unlikely that a traditional 3-year general pediatric residency will provide adequate experience to future CMC physicians. In response, core competencies for fellowship opportunities are being developed to meet this growing need.<sup>39</sup> The aim is to develop a sustainable pediatric workforce, well-trained and well-prepared to care for CMC and their families across the continuum.

## FUTURE DIRECTIONS AND CONCLUSIONS

We share our story, as one center's experience, to broaden the national discussion on CMC and models of care. Complex care programs are as unique as the CMC and families they serve, providers who render care, and infrastructure in which they operate. Empowered with this growing knowledge base, how would the ideal system of care for CMC look? If we were to have 30% of all pediatric health care dollars to invest in a system of caring for CMC and their families, how would we do this? Would we expand outpatient resources to further decrease hospitalizations for CMC? How would we blend our ambulatory provider and hospitalist efforts? What would be our measures of success? As the field of pediatric complex care matures, we encourage other centers share their stories too. Let's quantitatively and qualitatively learn from one another, strongly link our inpatient and outpatient processes, and build systems that support and sustain parents, providers, and health care systems in the care of CMC.

## REFERENCES

1. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*. 2011; 127(3):529–538
2. Berry JG, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings. *Health Aff (Millwood)*. 2014;33(12):2199–2206
3. Berry JG, Hall M, Hall DE, et al. Inpatient growth and resource use in 28 children's hospitals: a longitudinal, multi-institutional study. *JAMA Pediatr*. 2013; 167(2):170–177
4. Simon TD, Whitlock KB, Haaland W, et al. Effectiveness of a comprehensive case management service for children with medical complexity. *Pediatrics*. 2017; 140(6):e20171641
5. Lewis N. A primer on defining the triple aim. Institute for Healthcare

- Improvement. 2014. Available at: [www.ihl.org/communities/blogs/a-primer-on-defining-the-triple-aim](http://www.ihl.org/communities/blogs/a-primer-on-defining-the-triple-aim). Accessed April 17, 2020
6. Houtrow A, Coster W. Pediatric rehabilitation providers: leaders in advancing the care of children with disabilities. *Arch Phys Med Rehabil*. 2019;100(8):1578–1579
  7. de Camargo OK, Simon L, Ronen GM, Rosenbaum PL. *ICF: A Hands-on Approach for Clinicians and Families*. 1st ed. London, England: Mac Keith Press; 2019
  8. Yu JA, Schenker Y, Maurer SH, Cook SC, Kavliaratos D, Houtrow A. Pediatric palliative care in the medical neighborhood for children with medical complexity. *Fam Syst Health*. 2019;37(2): 107–119
  9. Feudtner C, Christakis DA, Connell FA. Pediatric deaths attributable to complex chronic conditions: a population-based study of Washington State, 1980-1997. *Pediatrics*. 2000;106(1, pt 2):205–209
  10. Feudtner C, Feinstein JA, Zhong W, Hall M, Dai D. Pediatric complex chronic conditions classification system version 2: updated for ICD-10 and complex medical technology dependence and transplantation. *BMC Pediatr*. 2014;14: 199
  11. Ellzey A, Valentine KJ, Hagedorn C, Murphy NA. Parent perceptions of quality of life and healthcare satisfaction for children with medical complexity. *J Pediatr Rehabil Med*. 2015;8(2): 97–104
  12. Mann K, Alvey JC, Marty C, Murphy NA. Health-related quality of life and family functioning of parents of children with medical complexity. *Curr Phys Med Rehabil Rep*. 2019;7(1):23–29
  13. Flanagan P, Tighe PM, Perrin J. The value proposition for pediatric care. *JAMA Pediatr*. 2019;173(12):1125–1126
  14. Smith GC, Pell JP. Parachute use to prevent death and major trauma related to gravitational challenge: systematic review of randomised controlled trials. *BMJ*. 2003;327(7429):1459–1461
  15. Dean W, Talbot S, Dean A. Reframing clinician distress: moral injury not burnout [published correction appears in *Fed Pract*. 2019;39(10):447]. *Fed Pract*. 2019;36(9):400–402
  16. Fayed N, Guttman A, Chiu A, et al. Family-provider consensus outcomes for children with medical complexity. *Dev Med Child Neurol*. 2019;61(9):1093–1100
  17. Shrank WH, Rogstad TL, Parekh N. Waste in the US health care system: estimated costs and potential for savings. *JAMA*. 2019;322(15):1501–1509
  18. Ahuja N, Zhao W, Xiang H. Medical errors in US pediatric inpatients with chronic conditions. *Pediatrics*. 2012;130(4). Available at: [www.pediatrics.org/cgi/content/full/130/4/e786](http://www.pediatrics.org/cgi/content/full/130/4/e786)
  19. Marty C, Alvey JC, Mann K, Murphy NA. Addressing over-medicalization in children with medical complexity. *Curr Phys Med Rehabil Rep*. 2019;7:6–10
  20. Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges among more medically complex children with special health care needs. *Arch Pediatr Adolesc Med*. 2011;165(11):1020–1026
  21. Maynard R, Christensen E, Cady R, et al. Home health care availability and discharge delays in children with medical complexity. *Pediatrics*. 2019; 143(1):e20181951
  22. Perkins J, Agrawal R. Protecting rights of children with medical complexity in an era of spending reduction. *Pediatrics*. 2018;141(suppl 3):S242–S249
  23. Feudtner C, Schall T, Nathanson P, Berry J. Ethical framework for risk stratification and mitigation programs for children with medical complexity. *Pediatrics*. 2018;141(suppl 3):S250–S258
  24. Flanagan F, Healy F. Tracheostomy decision making: from placement to decannulation. *Semin Fetal Neonatal Med*. 2019;24(5):101037
  25. Baker CD, Martin S, Thrasher J, et al. A standardized discharge process decreases length of stay for ventilator-dependent children. *Pediatrics*. 2016; 137(4):e20150637
  26. McKeon M, Kohn J, Munhall D, et al. Association of a multidisciplinary care approach with the quality of care after pediatric tracheostomy. *JAMA Otolaryngol Head Neck Surg*. 2019;145(11):1035–1042
  27. Prager JD, Baker CD. The multidisciplinary tracheostomy team: a parachute for tracheostomy-dependent children. *JAMA Otolaryngol Head Neck Surg*. 2019;145(11):1042–1043
  28. Cohen E, Berry JG, Sanders L, Schor EL, Wise PH. Status complexicus? The emergence of pediatric complex care. *Pediatrics*. 2018;141(suppl 3): S202–S211
  29. Casey PH, Lyle RE, Bird TM, et al. Effect of hospital-based comprehensive care clinic on health costs for Medicaid-insured medically complex children. *Arch Pediatr Adolesc Med*. 2011;165(5): 392–398
  30. Mosquera RA, Avritscher EBC, Samuels CL, et al. Effect of an enhanced medical home on serious illness and cost of care among high-risk children with chronic illness: a randomized clinical trial. *JAMA*. 2014;312(24): 2640–2648
  31. Gordon JB, Colby HH, Bartelt T, Jablonski D, Krauthoefer ML, Havens P. A tertiary care-primary care partnership model for medically complex and fragile children and youth with special health care needs. *Arch Pediatr Adolesc Med*. 2007;161(10):937–944
  32. Noritz G, Madden M, Roldan D, et al. A population intervention to improve outcomes in children with medical complexity. *Pediatrics*. 2017;139(1): e20153076
  33. Pordes E, Gordon J, Sanders LM, Cohen E. Models of care delivery for children with medical complexity. *Pediatrics*. 2018;141(suppl 3):S212–S223
  34. Murphy NA, Carbone PS; Council on Children With Disabilities; American Academy of Pediatrics. Parent-provider-community partnerships: optimizing outcomes for children with disabilities. *Pediatrics*. 2011;128(4):795–802

35. Murphy NA, Clark EB. Children with complex medical conditions: an under-recognized driver of the pediatric cost crisis. *Curr Treat Options Pediatr*. 2016; 2(4):289–295
36. Alvey JC, Valentine K, Wilkes J, et al. Indirect care utilization among children with medical complexity. *Curr Phys Med Rehabil Rep*. 2019;7:1–5
37. Ronis SD, Grossberg R, Allen R, Hertz A, Kleinman LC. Estimated nonreimbursed costs for care coordination for children with medical complexity. *Pediatrics*. 2019;143(1):e20173562
38. Langer CS, Antonelli RC, Chamberlain L, Pan RJ, Keller D. Evolving federal and state health care policy: toward a more integrated and comprehensive care-delivery system for children with medical complexity. *Pediatrics*. 2018; 141(suppl 3):S259–S265
39. Huth K, Newman L, Glader L. Core curricular priorities in the care of children with medical complexity: a North American modified Delphi study. *Acad Pediatr*. 2020;20(4): 558–564