

# Patterns and Costs of Health Care Use of Children With Medical Complexity

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## KEY WORDS

complex chronic conditions, technology assistance, children, health care utilization

## ABBREVIATIONS

CCC—complex chronic conditions  
CI—confidence interval  
CMC—children with medical complexity  
ICD-10—*International Classification of Diseases, 10th Revision*  
NI—neurologic impairment  
OHIP—Ontario Health Insurance Plan  
TA—technology assistance  
VLBW—very low birth weight

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**WHAT'S KNOWN ON THIS SUBJECT:** Children with medical complexity are high users of acute health care, but little is known about their service use across the continuum of care services and in the context of overall health care expenditures.



**WHAT THIS STUDY ADDS:** Although accounting for <1% of the child population, children with medical complexity use almost one-third of all pediatric health care expenditures and make multiple transitions across providers and health care settings.

## abstract



**BACKGROUND AND OBJECTIVE:** Health care use of children with medical complexity (CMC), such as those with neurologic impairment or other complex chronic conditions (CCCs) and those with technology assistance (TA), is not well understood. The objective of the study was to evaluate health care utilization and costs in a population-based sample of CMC in Ontario, Canada.

**METHODS:** Hospital discharge data from 2005 through 2007 identified CMC. Complete health system use and costs were analyzed over the subsequent 2-year period.

**RESULTS:** The study identified 15 771 hospitalized CMC (0.67% of children in Ontario); 10 340 (65.6%) had single-organ CCC, 1063 (6.7%) multiorgan CCC, 4368 (27.6%) neurologic impairment, and 1863 (11.8%) had TA. CMC saw a median of 13 outpatient physicians and 6 distinct subspecialists. Thirty-six percent received home care services. Thirty-day readmission varied from 12.6% (single CCC without TA) to 23.7% (multiple CCC with TA). CMC accounted for almost one-third of child health spending. Rehospitalization accounted for the largest proportion of subsequent costs (27.2%), followed by home care (11.3%) and physician services (6.0%). Home care costs were a much larger proportion of costs in children with TA. Children with multiple CCC with TA had costs 3.5 times higher than children with a single CCC without TA.

**CONCLUSIONS:** Although a small proportion of the population, CMC account for a substantial proportion of health care costs. CMC make multiple transitions across providers and care settings and CMC with TA have higher costs and home care use. Initiatives to improve their health outcomes and decrease costs need to focus on the entire continuum of care. *Pediatrics* 2012;130:e1463–e1470

Small groups of people account for a large proportion of health care costs.<sup>1</sup> There has been a growing focus on understanding these so-called high utilizers because it is thought that improving aspects of care delivery such as care coordination could improve their outcomes, reduce unnecessary health care utilization, and potentially begin to bend the cost curve trends in health care. Most studies and policy attention on the chronic disease management of high utilizers<sup>2,3</sup> have focused on adults.

Children with medical complexity (CMC) are defined as children who have complex underlying chronic health conditions that are typically associated with significant functional status limitations. There is a high prevalence of neurologic impairment (NI) and medical technology assistance (TA) among CMC.<sup>4</sup> Recent work from the United States suggests that CMC are major users of acute inpatient care,<sup>5,6</sup> driven, in particular, by frequent readmissions.<sup>7</sup> There is little information in the existing literature either on the types and amounts of health utilization CMC consume other than acute care services, nor is there information on the population prevalence of CMC. This information is essential for population-based health planning and policy.

The purposes of this article are to determine the population prevalence of CMC in Ontario, Canada's largest province with a population of almost 14 million, and to describe the clinical characteristics and patterns of health care utilization and costs in this population over a 2-year period.

## METHODS

### Study Data

Data for this retrospective cohort study were obtained from linked population-based administrative health databases from Ontario housed at the Institute for Clinical Evaluative Sciences, which uses a unique scrambled identifier to link an

individual's records across databases over time while preserving anonymity. Research ethics board approval for this study was received from Sunnybrook Health Sciences Centre.

### Data Sources

Study cohorts were constructed by using diagnostic codes from hospital (Discharge Abstract Database), emergency and same-day surgery (The National Ambulatory Care Reporting System), and physician billing (the Ontario Health Insurance Plan [OHIP]) data sets. The Canadian Institute for Health Information monitors the data quality of all hospital databases in Canada. The Registered Persons Database contains demographic and vital statistic data for all Ontario residents eligible for public health insurance.<sup>8</sup> Variables include a unique identifier, gender, date of birth, and, where applicable, date of death. Drug data came from the Ontario Drug Benefit Program, which covers low-income and most children at medically high risk. Home care data were obtained from the Home Care Database that records all provincial government in-home provider and case-management visits.

### Study Population

All children aged newborn to 16 years who were hospitalized between April 1, 2005, and March 31, 2007, were included for analysis. Hospitalizations included the birth admission. The discharge date of the first hospitalization with a CMC diagnosis was defined as the index date, marking the beginning of the 2-year follow-up period (last follow-up date March 31, 2009).

The study cohort comprised *International Classification of Diseases, 10th Revision* (ICD-10) diagnostic codes within 3 clinical categories relevant to CMC: NI, complex chronic conditions (CCCs), and TA (see Supplemental Table 3 for specific codes used). Although

there is no consensus definition for CMC, these clinical categories have been used in health services research focusing on this population.<sup>5,7,9,10</sup>

NI included diagnoses consistent with static or progressive neurologic, genetic, or other disease that typically results in either functional and/or intellectual impairment.<sup>10</sup> CCCs were defined by using the framework developed by Feudtner et al as "any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several organ systems or 1 organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center".<sup>11,12</sup> The CCCs are not intended to represent all chronic conditions of childhood. CCCs have been further subdivided into 9 separate diagnostic categories (by body system). For the purposes of this study, CCCs were subdivided into those affecting (1) a single body system (single CCCs) and (2) those affecting >1 body system (multiple CCCs). The 3 cohorts were mutually exclusive, and patients were sorted hierarchically: NI, then multiple CCCs, then single CCCs. Given the overarching importance of functional impairment in the definition of CMC, NI was placed at the top of the hierarchical categorization. Thus, all single or multiple body system CCCs attributed to neurologic disease (eg, cerebral palsy) or associated with NI (eg, Down syndrome) were classified as NI.

To ascertain TA, all previous hospital records from the index hospitalization back to birth were examined from diagnostic codes (Supplemental Table 3) and procedural codes (obtained from Canadian Classification of Procedures until 2002, then Canadian Classification of Interventions; codes available from authors on request) to identify insertions and removals of medical devices. Any child who had a recorded insertion or presence of a medical device,

without a subsequent removal, was classified as being TA, defined as medical technology used to maintain a child's health status such as gastrostomy, tracheostomy, cerebrospinal fluid ventricular shunt, permanent indwelling catheter, and pacemaker.

### Health Services Utilization

Each child's health system utilization and resulting costs were examined over the 2-year period immediately after their index hospitalization. System usage included hospital readmissions after the index admission, specialist and primary care physician visits, same-day surgeries, visits to the emergency department, and home care services. Costs for physician visits, medications, and home care services were estimated from fees paid directly to providers under fee-for-service payments. Costs for the remaining services were estimated from patient-specific institutional weighted case indices multiplied by either provincial average weighted case costs (for acute care and same-day surgeries) derived from case-mix groups methodology and resource intensity weighting calculation,<sup>13–17</sup> or by provincial average per visit costs (emergency department visits). Case weights were obtained from individual patient records; costs were obtained from the Ontario Ministry of Health and Long-Term Care Financial Information Management Branch Web site.<sup>18</sup> Detailed methods for case-costing by using administrative databases in Ontario are available in an online report.<sup>19</sup>

### Analysis

To put the spending of the cohort in the context of all health care spending on children, total annual mean health system costs were calculated for all recorded medical treatment and services for all OHIP-eligible children (<18 years) in each year from fiscal year 2005–2006 through 2008–2009 (average

$N = 2\,340\,060$  children/year). Among the study cohort of CMC, a log-linear regression model, adjusted for variables that may be associated with higher costs of care (age, gender, neighborhood income, rurality) was used to determine the independent association of high costs of care and patient characteristics. Age was analyzed categorically (0–1 year, 1–4 years, 5–9 years, 10–13 years, and 14–16 years).

## RESULTS

There were 340 786 children hospitalized between April 2005 and March 2007, and 15 771 (4.6%) were CMC, representing 0.67% of OHIP-eligible children in Ontario.

### Clinical and Demographic Characteristics

Of the cohort of 15 771 CMC, 4368 (27.6%) had NI, 1063 (6.7%) had CCCs affecting multiple organ systems, and 10 340 (65.6%) had a single organ-system CCC at the time of the index admission (Table 1 and Fig 1). TA was present in 1863 (11.8%) of the overall CMC, and significantly different across the 3 groups ( $P < .001$ ), most commonly in CMC with NI (20.0%). The most common form of TA was gastrostomy tube ( $n = 737$ ). More than half of CMC were aged  $\geq 1$  year, and 55.4% were boys. Newborns accounted for 33.4% of the cohort; very low birth weight (VLBW) newborns (birth weight <1000 g) accounted for 4.9% of the cohort.

### Mortality, Readmissions, Home Care Use, and Outpatient Physician Providers

See also Table 2.

#### Mortality

Mortality during index admission was lowest in children with 1 CCC without TA (2.2%) and the highest in children with  $\geq 2$  CCCs without TA (6.3%). Mortality in the 2 years after the index admission

was lowest in children with 1 CCC without TA (1.7%) and highest in children with NI and TA (7.4%).

#### Hospital Readmission

The lowest 30-day readmission rate was observed among children with 1 CCC without TA (12.6%) and the highest among children with multiple CCC with TA (23.7%). Two-year readmission rates were lowest for children with a single CCC without TA (39.0%) and highest among children with multiple CCC with TA (78.3%).

#### Home Care Use

Overall, 36% of CMC received home care services over the 2-year follow-up period. Use was highest in CMC with TA: 81.0% for NI with TA, 73.0% for multiple CCC with TA, and 63.8% for single CCC with TA. Overall, nursing, therapy, and case management visits were the most common home care services used (by 20.5%, 22.0%, and 24.7% of the cohort, respectively).

#### Number of Physicians

CMC had a median of 13 distinct physicians who provided outpatient care, and these were from a median of 6 distinct medical specialties. Children with TA consistently had more distinct physicians and specialties providing care across the 3 CMC subgroups.

### Health Care Costs

The estimated total 2-year expenditure of the cohort of 15 771 CMC was \$838 824 141 (Canadian) with a mean of \$53 188 and a median of \$17 372 per patient (Supplemental Table 4). Given an annualized health care cost for all Ontario children of \$1 280 827 414/year over the study period, the 2-year expenditure on CMC accounted for 32.7% of total spending on health care for children in Ontario.

The index hospitalization accounted for 51.8% of the total costs of care for the CMC cohort. Subsequent rehospitalization costs accounted for 27.2%, home

**TABLE 1** Cohort Clinical and Demographic Characteristics

Characteristics	NI		Multiple CCC		Single CCC		
	Overall	TA	No TA	TA	No TA	TA	No TA
	<i>n</i> = 15 771	<i>n</i> = 873	<i>n</i> = 3495	<i>n</i> = 152	<i>n</i> = 911	<i>n</i> = 838	<i>n</i> = 9502
Age group, <i>n</i> (%)							
Newborn <sup>a</sup>	5262 (33.4)	46 (5.3)	716 (20.5)	41 (27.0)	558 (61.3)	148 (17.7)	3753 (39.5)
Infancy (nonnewborn)	2226 (14.1)	52 (6.0)	367 (10.5)	30 (19.7)	125 (13.7)	68 (8.1)	1584 (16.7)
1–4 y	2959 (18.8)	198 (22.7)	899 (25.7)	44 (28.9)	98 (10.8)	232 (27.7)	1488 (15.7)
5–9 y	2430 (15.4)	263 (30.1)	705 (20.2)	25 (16.4)	57 (6.3)	207 (24.7)	1173 (12.3)
10–13 y <sup>b</sup>	2212 (14.0)	251 (28.8)	643 (18.4)		61 (6.7)	148 (17.7)	1098 (11.6)
14–16 y <sup>b</sup>	682 (4.3)	63 (7.2)	165 (4.7)		12 (1.3)	35 (4.2)	406 (4.3)
Gender, female	7030 (44.6)	384 (44.0)	1520 (43.5)	74 (48.7)	421 (46.2)	346 (41.3)	4285 (45.1)
Technology device, <i>n</i> (%)							
Gastrostomy	737 (4.7)	417 (47.8)		72 (47.4)		248 (29.6)	
Tracheostomy <sup>c</sup>	162 (1.0)	58 (6.6)				87 (10.4)	
CSF shunt <sup>c</sup>	359 (2.2)	322 (36.9)				36 (4.3)	
Evacuation tubes	227 (1.4)	53 (6.1)		43 (28.3)		131 (15.6)	
Renal support	264 (1.7)	32 (3.7)		23 (15.1)		209 (24.9)	
Cardiac support	188 (1.1)	17 (1.9)		15 (9.9)		156 (18.6)	
Other device <sup>c,d</sup>	30 (0.2)	17 (1.9)				10 (1.2)	

CSF, cerebrospinal fluid.

<sup>a</sup> This includes 767 VLBW (<1000 g) newborns (4.9% of entire cohort).

<sup>b</sup> Eighteen children (11.4%) aged 10 to 16 y combined. Individual cell data not displayed because of small sample size to maintain confidentiality.

<sup>c</sup> Twenty-one (13.8%) with multiple CCCs with TA had a tracheostomy, CSF shunt, or other device. Individual cell data not displayed because of small sample size to maintain confidentiality.

<sup>d</sup> Other includes devices such as indwelling pumps (eg, baclofen pump).

care costs for 11.3%, and out-patient physician services for 6.0% of total costs. Mean per patient total costs for all care excluding the index hospitalization was \$17 704 for 9502 children in the CMC cohort with a single CCC without TA, and was \$60 903 for children with single CCC with TA, \$78 324 for children with NI with TA, and \$86 181 for children with multiple CCC with TA (Fig 2). Acute care readmission was the largest contributor to cost after the index hospitalization among all groups with the exception of the NI with TA and the multiple CCC with TA groups, for whom home

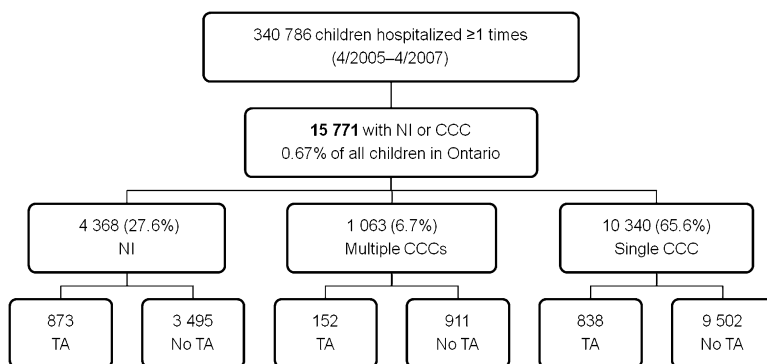
care was the largest contributor to cost. Home care costs accounted for a much larger proportion of total costs in children with TA than in those without TA;  $P < .001$ . Emergency department use was a relatively small contributor to cost among all the groups (0.4% of overall costs). Among the 747 VLBW newborns, the index hospitalization accounted for 86.6% of all costs.

A multivariate regression analysis was conducted to estimate relative costs across various clinical characteristics while adjusting for age, gender, birth weight, neighborhood income quintile,

and rurality. With the base case of a single CCC with no TA, adjusted relative total costs were 3.5 (confidence interval [CI] 2.9–4.1) for multiple CCC with TA, 2.4 (CI 2.2–2.6) for single CCC with TA, 2.2 (CI 2.0–2.3) for NI with TA, 2.2 (CI 2.0–2.4) for multiple CCC alone, and 0.9 (CI 0.8–0.9) for NI alone.

## DISCUSSION

CMC experiencing a hospitalization over a 2-year period constitute approximately two-thirds of a percent of the population of children in Ontario but account for almost one-third of health care spending on all children. Out-patient care by many physicians and specialties is common among CMC, and 30-day readmission rates are high, indicating that coordination of care is an important issue for this cohort. The use of the emergency department, a frequent target for improving efficiencies in health care delivery for broad populations including other populations of children with chronic diseases (eg, asthma), is not a major driver of costs for CMC. There are large differences in health care costs and outcomes,



**FIGURE 1**

Construction of the cohort of children with CCCs and NIs with or without TA.

**TABLE 2** Clinical Outcomes and Health Resource Utilization Patterns Among the Cohort

	Overall <i>n</i> = 15 771	NI		Multiple CCC		Single CCC		<i>P</i> Value
		TA	No TA	TA	No TA	TA	No TA	
		<i>n</i> = 873	<i>n</i> = 3495	<i>n</i> = 152	<i>n</i> = 911	<i>n</i> = 838	<i>n</i> = 9502	
<b>Mortality</b>								
Index hospitalization death, <i>n</i> (% users)	417 (2.6)	15 (1.7)	101 (2.9)	9 (5.9)	57 (6.3)	26 (3.1)	209 (2.2)	<.001
Death within 2 y postindex, <i>n</i> (%)	398 (2.5)	65 (7.4)	80 (2.3)	6 (3.9)	34 (3.7)	50 (6.0)	163 (1.7)	<.001
<b>Readmissions, <i>n</i> (%)</b>								
30-d readmissions	2081 (13.2)	144 (16.5)	381 (10.9)	36 (23.7)	163 (17.9)	160 (19.1)	1197 (12.6)	<.001
30-d nonelective readmissions	1575 (10.0)	128 (14.7)	337 (9.6)	28 (18.4)	125 (13.7)	114 (13.6)	843 (8.9)	<.001
2-y readmissions	6952 (44.1)	586 (67.1)	1505 (43.1)	119 (78.3)	487 (53.5)	550 (65.6)	3705 (39.0)	<.001
2-y nonelective readmissions	5436 (34.5)	492 (56.4)	1238 (35.4)	97 (63.8)	375 (41.2)	437 (52.1)	2797 (29.4)	<.001
<b>Home care use<sup>a</sup></b>								
Home care use, <i>n</i> (%)	5670 (36.0)	707 (81.0)	1753 (50.2)	111 (73.0)	360 (39.5)	535 (63.8)	2204 (23.2)	<.001
No. different HC service types used, median (IQR)	2 (2–4)	4 (2–5)	3 (2–4)	3 (2–4)	2 (2–3)	2 (2–4)	2 (1–3)	<.001
<b>Drug use<sup>a</sup></b>								
Ontario Drug Benefit claims, <i>n</i> (%)	4954 (31.4)	565 (64.7)	1301 (37.2)	104 (68.4)	326 (35.8)	436 (52.0)	2222 (23.4)	<.001
No. medications, median (IQR)	6 (3–10)	9 (5–14)	5 (3–9)	9 (5–15)	6 (3–11)	8 (4–12)	5 (2–9)	<.001
<b>Outpatient use<sup>a</sup></b>								
No. primary care visits, median (IQR)	12 (6–20)	9 (4–14)	10 (5–18)	14 (8–23)	18 (11–25)	10 (5–18)	13 (7–20)	<.001
No. distinct physicians, median (IQR)	13 (8–20)	19 (12–27)	13 (8–20)	24 (17–38)	16 (10–27)	18 (11–29)	11 (7–18)	<.001
No. distinct specialties, median (IQR)	6 (4–8)	8 (6–10)	6 (4–8)	9 (7–12)	7 (5–9)	7 (5–10)	5 (4–7)	<.001
No. same-day surgeries, median (IQR) <sup>a</sup>	1 (1–2)	1 (1–2)	1 (1–2)	1 (1–2)	1 (1–2)	1 (1–2)	1 (1–1)	.003
No. unplanned ED visits, median (IQR) <sup>a</sup>	2 (1–5)	3 (2–6)	3 (1–5)	3 (2–6)	3 (1–5)	2 (1–5)	2 (1–4)	<.001

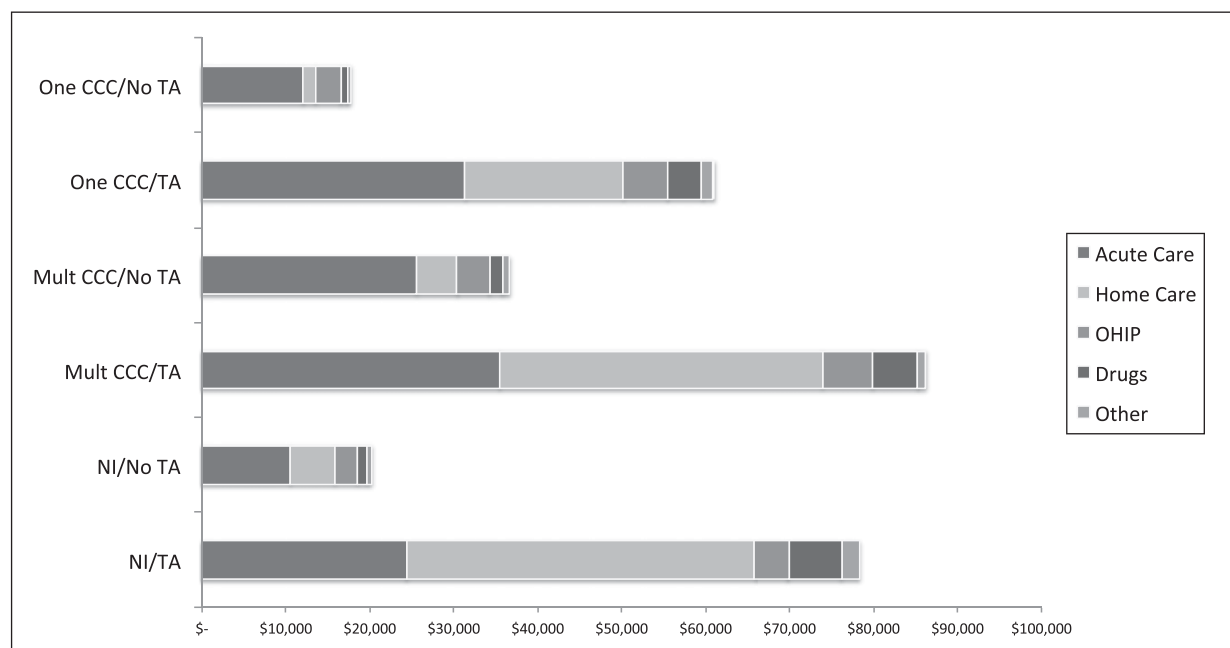
HC, health care; IQR, interquartile range.

<sup>a</sup> Within 2 y post-index hospitalization.

especially mortality, across different subgroups. For some (eg, VLBW newborns), a single index hospitalization accounts for the majority of costs. TA is a strong independent cost predictor due,

in large part, to the substantial home care needs that are required to manage these children. In those CMC without TA, acute care hospital services account for most of the health care costs.

This study adds to the existing literature by providing a comprehensive population-based overview of health care utilization and costs for CMC over a 2-year period. We observed a larger proportion of

**FIGURE 2**

Cost breakdown by cohort subgroups (excluding index hospitalization). All costs expressed as mean cost (C\$) per patient in each subgroup. Mult, multiple; OHIP, Ontario Health Insurance Plan (physician billing); Other, same day surgery, emergency department visits, inpatient rehabilitation and complex continuing care.

costs attributable to CMC than reported in previous studies of more limited populations of these children. Buescher et al found that 0.2% of children with Medicaid insurance had TA, and they accounted for 6.8% of the state's child Medicaid expenditures. The study did not describe broader diagnostic groups nor children who used other types of insurance.<sup>20</sup> Neff and colleagues found that children with "catastrophic" chronic conditions, including diagnoses that would be considered CCCs or NI such as quadriplegia, cystic fibrosis, and spina bifida,<sup>21–23</sup> accounted for 0.4% of children in a health plan of 31 253 children in Washington State yet were responsible for 11% of health care charges and 24% of all pediatric hospital charges.

It is notable that mortality rates are not high for the cohort of CMC in Ontario. From the index hospitalization through 2 years, only 5.1% of the cohort died. This is consistent with the finding of increasing age of death of children with a variety of congenital anomalies<sup>24–26</sup> and NI<sup>27,28</sup> in part related to increased use of technology to sustain their health. Although the overall prevalence of some conditions have declined (eg, neural tube defects),<sup>29</sup> for others it has increased substantially. For instance, the incidence of live births <500 g in Canada has tripled from 1985 to 2003,<sup>30</sup> and although there have been decreases in mortality among these infants, there has not been a consistent decline in severe neurodevelopmental sequelae.<sup>31</sup>–<sup>34</sup> Overall, the proportion of child health care spending for CMC, particularly in acute care, is increasing,<sup>5,6</sup> and CMC populations may increase over time.

There are a number of important limitations to this study. We ascertained our cohort from hospitalization, so we did not capture CMC who were never hospitalized over 2 years. Therefore, we likely underestimated population

prevalence and overall cost and may have overestimated average cost. We lack complete data on rehabilitation utilization (inpatient and outpatient), private drug and home care coverage, and care from a relatively small number of providers who do not bill fee-for-service (eg, nurse practitioners who provide primary care in rural areas). Indirect health costs, particularly those associated with family caregiving, were not captured; such indirect costs can be substantial for families of children with complex health needs.<sup>35–37</sup> Our inclusion criteria were limited to the use of ICD-10 codes. We did try to incorporate some nondiagnostic complexity criteria such as TA, but other important domains such as family-identified needs,<sup>38</sup> psychosocial complexity, and a direct measure of functional status were not captured. The sensitivity and specificity of the diagnostic codes used in this study have not been formally assessed, and thus individual patients may have not met criteria for CMC (eg, a child with a repaired congenital heart disease with no other complexities may not be considered complex by some). However, even among those without TA (eg, single CCC without TA), some children had multiple diagnoses within an organ system (Supplemental Table 5), and, on an aggregate level, system-level costs were substantial.

Despite these limitations, the implications of our findings are that a small group of children who are easily identifiable at hospital discharge go on to use multiple sources of health care services and account for an exceedingly disproportionate amount of child health spending in the 2 years after an index hospitalization. This population of high utilizers may be considered a priority for targeting care coordination interventions, particularly given that hospitals are increasingly pressured to

discharge their patients sooner without compromising their patients' risk for readmission. There is emerging evidence that structured complex care interventions such as intensive care coordination may attenuate acute care expenditures for CMC.<sup>39–42</sup> Previous studies have reported that the care these children receive is often fragmented, uncoordinated, and associated with nonproactive care planning and health information mismanagement,<sup>43</sup> and the family burden of caring for CMC at home is associated with detrimental caregiver health<sup>36,44</sup> as well as financial,<sup>45</sup> marital,<sup>46</sup> and employment<sup>35</sup> discord. Observational data seem to suggest that intensive outpatient care coordination interventions may prevent some acute care utilization<sup>39,40,47</sup> and improve family well-being<sup>41,47</sup> in complex pediatric populations. However, interpretation of these findings is limited by the lack of a control group,<sup>48</sup> particularly given that many studies use a pre-post design with hospital-based ascertainment, and resource consumption can be disproportionately high (51.7% of total costs in our study) in a single hospitalization. There has been, in recent years, an exponential growth in the number of clinical programs for CMC across North America, particularly in hospital-based settings,<sup>4,49</sup> but our findings suggest that, particularly for some subgroups (eg, those with TA), efforts to extend these models to the home and community care setting may be warranted. Future work needs to determine which interventions can decrease costs associated with unnecessary utilization and improve outcomes for this vulnerable group of children.

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