Variation in Child Health Care Utilization by Medical Complexity

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Abstract Children with medical complexity (CMC) have multiple specialty need, technology dependence, and high health care utilization. The objective of this study is to profile types of pediatric health care utilization and costs by increasing levels of medical complexity. This is a cross-sectional study of the 2007, 2008 and 2009 Full-Year Data Sets from the Medical Expenditure Panel Survey. Medical complexity was defined by a higher number of positive items from the five question children with special health care needs (CSHCN) Screener. CMC were defined by ≥4 positive screener items. Outcomes included the number of inpatient, outpatient, and emergency department visits, associated costs and diagnoses, and reported satisfaction. ICD-9 codes were grouped by Clinical Classifications Software. Of 27,755 total study subjects ≤17 years, 4,851 had special needs and 541 were CMC. Older age, male gender, white/non-Hispanic race/ethnicity, and public insurance were all associated with medical complexity (all $p < 0.001$). CMC had an annual mean of 19 annual outpatient visits ($616) and 0.26 inpatient visits ($3,308), with other significant cost drivers including home health ($2,957) and prescriptions ($2,182). The most common reasons for non-CSHCN and less-complex CSHCN outpatient visits were viral illnesses, while the main reasons for CMC visits were for mental health. Compared to families without CSHCN, those with CMC have, on average, lower satisfaction with health care (8.4 vs. 8.9 out of 10, $p < 0.001$). Health care models for CMC should account for mental health conditions that may be driving high numbers of outpatient encounters.

Keywords Children with special health care needs · Complex care · Complex chronic conditions · Health care disparities · Medical home

Abbreviations
CSHCN	Children with special health care needs
MEPS	Medical Expenditure Panel Survey
CCS	Clinical Classification Software
ED	Emergency department

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Introduction

A very small number of all children (0.4–0.7 %) are recognized as extreme health care resource utilizers by incurring 11–33 % of total pediatric health care costs [1, 2]. The vast majority of such children have complex care needs and are known as children with medical complexity (CMC), a subgroup of children with special health care needs (CSHCN) with the highest medical care needs and associated costs [3]. Examples of CMC include children with cerebral palsy and developmental delay who require technology assistance for nutrition and adequate ventilation. CMC have a high burden of care for families [4] and are at risk for frequent hospitalizations and recurrent admissions [5].

Children with medical complexity are attracting attention from health care systems and policymakers because of their high cost relative to their small numbers [6]. Accordingly, CMC are inviting targets for system intervention to bend the health care cost curve [7]. It is thought that inpatient hospital use accounts for the largest proportion of health care spending for CMC, upwards of 80 % of total costs [1, 2]. The number of children with complex chronic conditions in hospital settings is rising, with respiratory illnesses and technology malfunctions as the most common reasons for admission [5, 8–10]. Accordingly, hospital-based services for CMC have targeted excess inpatient and emergency room use [11–13]. However, outcomes data on these programs are limited by use of hospital-based data and inclusion of children who tend to have a high number of hospital-based encounters.

There are relatively little data on the overall profile of CMC health care service use across the care continuum. One study from North Carolina found that of the 0.2 % of Medicaid-insured children with technology dependence in 2004, 54 % were hospitalized, with hospitalizations accounting for just under 30 % of the total costs [14]. This finding is very different than studies suggesting 80 % of CMC costs are in the inpatient setting, underscoring how little we know about the types, frequency, and cost burden for CMC across the care continuum [6]. A fuller understanding of service use and costs across the care continuum would help tailored care systems to the needs of CMC, and define the factors that contribute to potentially preventable costs for payers and systems.

The objective of this study is to characterize the health care use of children by varying levels of medical complexity and the quality of care these children receive. We hypothesized that CMC, identified through a screener-based algorithm in a national data set, will have higher numbers of inpatient admissions, emergency department (ED) visits, and outpatient visits compared to children without complex care needs, and that the most frequent type of visit across settings will be due to acute respiratory illness or technology malfunction. We also hypothesized that higher medical complexity would be associated with lower perceived quality of care.

Methods

This is a cross-sectional study design using the 2007, 2008, and 2009 Full-Year Data Sets from the Medical Expenditure Panel Survey (MEPS). The MEPS is a national survey sponsored by the Agency for Healthcare Research and Quality which provides estimates of health care services used, their costs, and the payment methods. MEPS study subjects are drawn from a nationally representative subsample of the noninstitutionalized civilian population previously enrolled in the National Health Interview Survey. Household data are collected in five computer-assisted, in-person interviews held over a two-year period. Oversampling gathers information on demographic groups of particular interest. The Full-Year Data Sets contain demographic information, overall health status, CSHCN status, and cost and health service utilization for a specific calendar year. We used 3 years of data to account for a small number of study subjects categorized into medically complex subgroups. Combining MEPS data sets has been used in previous studies [15, 16]. Because the data is publicly available and de-identified, the study received exempt status from our Institutional Review Board.

Study Population

All children who were 0–17 years of age at the time of the survey were included for analysis. CSHCN were identified by the CSHCN Screener, a five-question screen of functioning and health care service use that identifies special needs by a positive answer to any of the five screener items. The five items include a need for prescription medication, need for medical care, functional limitation, need for special therapies, or treatment/counseling for a developmental/behavioral problem [17]. Individual Screener items have been associated with variation in health care expenditures reported in MEPS [18].

At present there is no consensus of determining medical complexity through survey-based secondary data. We elected the method of utilizing the number of positive Screener questions, as a higher number of positive questions has been described to have a linear relationship with increasing health care costs, missed school days, and increasing number of ED visits [19]. We categorized all children by whether they were positive for 0, 1, 2, 3, or ≥ 4 of 5 CSHCN Screener questions. We empirically defined CMC as children who qualified on the highest number of Screener questions, due to prior literature describing a correlation with Screener questions and higher reported health care utilization, poor health status, higher unmet needs, and need for subspecialty care and ancillary services [19], which map to reported domains of medical complexity [3]. Given past literature, we reasoned that the higher resource use in this subset of CSHCN is likely due to medical complexity. We combined 4 and 5 positive questions because of the relatively low number of children in these specific groups; this is consistent with past use of the CSHCN Screener in this manner [19]. Children who did not qualify for special health care needs on any criteria were regarded as "healthy".

We separately examined the utility of a functional status-based classification method since specific combinations

of Screener questions have been described to have associations with differing levels of complexity [19]. Under this method, CMC were defined as having functional limitations, regardless of positive answer to any other screening question, since the functional limitation group has been associated with poorer health status and more complex health care needs [20]. A cross-tabular analysis of the two methods of defining complexity—number of positive responses on the CSHCN Screener versus functional status-based—found that 468 out of 541 of the children who qualified on ≥4 of 5 CSHCN Screener questions fell in the functional limitations category of the functional status-based categorization. Accordingly, we limit reporting to results based on increasing number of positive screener questions due to the linear relationship with increasing cost. Our rationale is that a description of the highest cost children would be of most interest to health care policymakers.

Variables

The main predictor variable was increasing level of medical complexity, defined by ordinal categories representing an increasing number of positive responses to the CSHCN Screener.

Outcome variables included:

- Number of inpatient, outpatient, and ED visits per year.
- Reasons for visits. MEPS contains up to four caregiver-reported reasons for health care encounters. Each encounter reason is matched to an ICD-9 diagnosis code and subsequently into a Clinical Classification Software (CCS) group, forming clinically homogenous classifications. For all encounters, we tabulated all possible reasons for visits and then examined the top ten non-mutually exclusive reasons. For conciseness we report the top three CCS groups identified for each patient. The methodology does not report the primary reason for the visit but still allows tabulation of the reasons for visits.
- Reported expenses, by inpatient, outpatient, and ED visits, and total expenses. Because inpatient, outpatient, and ED expenses did not explain much of the total expenses for the 4/5 group, we also examined prescription and home health expenses. Expenses are expressed in 2009 dollars, with Consumer Price Index health care cost adjustments of 1.061 for 2007 and 1.033 for 2008.
- Specific health care quality measures based on Consumer Assessment of Healthcare Providers and Systems (CAHPS®) survey instruments, including parents reporting whether child's doctors (1) listen (2) explain things easily, (3) show respect, and (4) spend enough time with the parent. We matched the responses (never,

sometimes, usually, always) to a 1–4 Likert scale. Overall satisfaction with care in the prior 12 months was reported on a 0–10 Likert scale, with 10 being the highest.

Demographics included age (grouped by ≤1, 2–4, 5–12, and 13–17 years at time of survey), gender, race/ethnicity (white/non-Hispanic, black/non-Hispanic, Hispanic, and other), insurance (Medicaid/SCHIP, Private, Uninsured/Other at time of survey), primary language at home (English, Spanish/other), and whether the child has a usual source of care.

Analytic Plan

All research and analyses were conducted in accord with prevailing ethical principles. Data from the 2007, 2008, and 2009 Full-Year Data Sets were combined. Analyses accounted for person-weight variables, with the person-weight variable divided by 3 (the number of years being pooled) to produce "average annual" estimates of totals. Stratum and cluster variables accounted for children who, due to their enrollment panels, spanned two consecutive years of the Full-Year Data Sets. All analyses were conducted using SAS 9.3 (Cary, NC), using the appropriate procedures and options to handle complex survey designs.

For the descriptive analyses of demographics, the overall association was tested using proc surveyfreq, with p values corresponding to the Rao-Scott Chi square test of association. Pairwise analyses examined individual comparisons within groups of complexity, using Tukey's adjustment for multiple comparisons. For demographics, proc surveyreg (for age) and proc surveylogistic (for gender, race/ethnicity, insurance, language at home, and usual source of care) were employed. For satisfaction, number of visits, and expenses models, proc surveyreg was used, with adjustment for age, gender, race/ethnicity, and insurance status. Regression diagnostic plots for the expenses models showed no heteroskedasticity of the residuals and ∼0.5 % of the residuals having z scores greater than 3. We considered these outliers too few to warrant data transformation or curtailed analyses. Because health service utilization frequency may vary by age, we stratified analyses by age group and found no difference in pairwise comparison trends, hence overall results are tabulated.

Results

There were 27,755 (unweighted) individual study subjects with positive weights among the 2007, 2008, and 2009 Full-Year Data Sets. Among study subjects, 22,894 (unweighted) children had no special health care needs;

Table 1 Demographics of study subjects by number of positive responses to CSHCN Screener

| | Number of CSHCN Screener Questions (N) | | | | | | | | | | Total | |
	0	Row %	1	Row %	2	Row %	3	Row %	4–5	Row %	N	% weighted
Age*												
≤1 Year	2,669	92.2	151	5.0	41	1.5	24	0.7	17	0.6	2,902	11.33
2–4 Years	4,092	87.4	318	7.5	126	2.8	52	1.2	54	1.1	4,642	16.54
5–12 Years	9,976	78.7	1,271	11.2	536	4.5	358	2.8	333	2.8	12,474	43.96
13–17 Years	6,157	77.2	910	13.4	321	4.5	212	3.0	137	1.8	7,737	28.18
Mean (SE)	8.2 (0.02)		10.0 (0.06)		9.8 (0.07)		10.2 (0.08)		9.5 (0.09)			
Pairwise p values#	1, 2, 3, 4		0, 4		0, 3, 4		0, 2, 4		0, 1, 2, 3			
Gender*												
Male	11,398	78.3	1,488	11.4	623	4.7	408	2.9	374	2.7	14,291	51.05
Female	11,496	84.3	1,162	9.6	401	3.0	238	1.8	167	1.3	13,464	48.95
Pairwise p values#	1, 2, 3, 4		0, 4		0		0		0, 1			
Race/ethnicity*												
White, non-hispanic	7,503	78.6	1,156	12.0	445	4.5	283	2.6	246	2.3	9,633	55.97
Black non-hispanic	4,637	80.3	647	10.9	250	4.1	162	2.7	120	2.0	5,816	14.25
Hispanic	8,763	87.8	644	7.0	245	2.5	147	1.5	123	1.3	9,922	21.89
Other race	1,991	83.3	203	9.2	84	3.2	54	2.5	52	1.9	2,384	7.89
Pairwise p values#	1, 2, 4		0		0				0			
Insurance*												
Medicaid/SCHIP	11,421	79.4	1,286	9.6	570	4.3	416	3.4	389	3.3	14,082	36.36
Private	9,203	81.6	1,180	11.4	403	3.9	198	1.8	132	1.3	11,116	54.77
Uninsured/other	2,270	86.9	184	8.5	51	1.9	32	1.8	20	0.8	2,257	8.88
Pairwise p values#	1, 3, 4		0, 3, 4		3, 4		0, 1, 2		0, 1, 2			
Language at home*												
English	16,128	79.1	2,304	11.7	895	4.3	583	2.7	463	2.2	20,373	83.51
Spanish/other	6,751	92.1	345	4.6	125	1.6	62	0.7	77	0.9	7,360	16.49
Pairwise p values#	1, 2, 3, 4		0		0		0		0			
Has usual source of care*												
Yes	19,732	80.1	2,460	11.1	962	4.2	611	2.5	506	2.1	24,271	89.75
No	2,953	91.1	178	5.6	53	1.2	33	1.0	31	1.1	3,248	10.25
Pairwise p values#	1, 2, 3, 4		0		0		0		0			

* Significant by Rao-Scott Chi square at $p < 0.001$

For pairwise p value, 0 = significantly different from 0 positive Screener criteria, 1 = significantly different from 1 positive Screener criterion, 2 = significantly different from 2 positive Screener criteria, 3 = significantly different from 3 positive Screener criteria, 4 = significantly different from 4 or 5 positive Screener criteria. All pairwise p values significant at $p < 0.05$ (using Tukey's adjustment for multiple comparisons) and adjusted for age, gender, race/ethnicity, and insurance status

SE standard error of the mean

2,650 responded positively to one question on the CSHCN Screener; 1,024 responded to 2 questions; 646 responded to 3 questions; and 541 (CMC) responded to 4 or 5 questions. Children who were older tended to have more special health care needs (Table 1) although the CMC group tended to be somewhat younger (9.5 years) than the other groups of CSHCN (9.8–10.2 years). Male gender was more likely to be associated with special health care needs, and particularly medical complexity. White/non-Hispanic race/ethnicity and English language at home were more likely to be associated with special health care needs overall, although no trend was

seen with increasing complexity. Children with Medicaid/SCHIP insurance status were more likely to have special health care needs, particularly medical complexity.

Number of Visits

The numbers of reported inpatient, outpatient, and ED visits are found in Table 2. Children without special health care needs had a mean of 0.03 inpatient visits, 2.6 outpatient visits, and 0.21 ED visits per year. For all categories of visits, an increasing number of visits was associated with

an increasing number of qualifying Screener questions. CMC had a mean of 0.26 inpatient visits, 19.0 outpatient visits, and 0.50 ED visits per year. Youngest children had the highest number of overall encounters (26.1 outpatient visits for CMC ≤1 year versus 14.2 outpatient visits for CMC 13–17 years).

Table 2 Number of inpatient, outpatient, and ED visits per year by number of positive responses to CSHCN Screener

	Number of CSHCN Screener Criteria				
	0	1	2	3	4/5
Number of Inpatient visits[*]					
Mean (SE)	0.03 (0.002)	0.06 (0.002)	0.12 (0.004)	0.22 (0.005)	0.26 (0.005)
Pairwise p values[#]	1, 2, 3, 4	0, 2, 3, 4	0, 1, 3, 4	0, 1, 2, 4	0, 1, 2, 3
Number of Outpatient visits[*]					
Mean (SE)	2.64 (0.02)	5.98 (0.05)	9.86 (0.09)	12.95 (0.22)	19.00 (0.32)
Pairwise p values[#]	1, 2, 3, 4	0, 2, 3, 4	0, 1, 3, 4	0, 1, 2, 4	0, 1, 2, 3
Number of ED visits[*]					
Mean (SE)	0.21 (0.002)	0.31 (0.004)	0.36 (0.006)	0.49 (0.017)	0.50 (0.009)
Pairwise p values[#]	1, 2, 3, 4	0, 2, 3, 4	0, 1, 3, 4	0, 1, 2, 4	0, 1, 2, 3

[*] Significant by Rao-Scott Chi square at $p < 0.001$

[#] For Pairwise p value, 0 = significantly different from 0 positive Screener criteria, 1 = significantly different from 1 positive Screener criterion, 2 = significantly different from 2 positive Screener criteria, 3 = significantly different from 3 positive Screener criteria, 4 = significantly different from 4 or 5 positive Screener criteria. All pairwise p values significant at $p < 0.001$ (using Tukey's adjustment for multiple comparisons) and adjusted for age, gender, race/ethnicity, and insurance status

SE standard error of the mean

Table 3 Expenses of child per year by number of positive responses to CSHCN Screener (in 2009 dollars)

	Number of CSHCN Screener Criteria				
	0	1	2	3	4/5
Total health care expenses[*]					
Mean (SE)	804 (12.5)	1,766 (26.4)	4,593 (46.2)	5,097 (73.4)	11,388 (492.7)
Pairwise p values[#]	1, 2, 3, 4	0, 2, 3, 4	0, 1, 3, 4	0, 1, 2, 4	0, 1, 2, 3
Total inpatient expenses[*]					
Mean (SE)	191 (7.8)	272 (15.2)	1,399 (21.0)	1,421 (35.6)	3,308 (120.2)
Pairwise p values[#]	1, 2, 3, 4	0, 2, 3, 4	0, 1, 4	0, 1, 4	0, 1, 2, 3
Total home health expenses[*]					
Mean (SE)	0 (1.3)	3 (1.7)	68 (7.2)	286 (6.1)	2,957 (53)
Pairwise p values[#]	1, 2, 3, 4	0, 2, 3, 4	0, 1, 3, 4	0, 1, 2, 4	0, 1, 2, 3
Total prescription medication expenses[*]					
Mean (SE)	14 (1.6)	459 (8.5)	1,099 (23.2)	1,312 (19.4)	2,182 (30.9)
Pairwise p values[#]	1, 2, 3, 4	0, 2, 3, 4	0, 1, 3, 4	0, 1, 2, 4	0, 1, 2, 3
Total outpatient expenses[*]					
Mean (SE)	43 (2.2)	95 (8.6)	560 (10.3)	422 (26.7)	616 (148.5)
Pairwise p values[#]	1, 2, 3, 4	0, 2, 3, 4	0, 1, 3	0, 1, 2	0, 1
Total ED Expenses[*]					
Mean (SE)	84 (8.8)	123 (7.2)	160 (10.0)	196 (11.5)	221 (9.7)
Pairwise p values[#]	1, 2, 3, 4	0, 2, 3, 4	0, 1, 3, 4	0, 1, 2	0, 1, 2

[*] Significant by Rao-Scott Chi square at $p < 0.001$

[#] For pairwise p value, 0 = significantly different from 0 positive Screener criteria, 1 = significantly different from 1 positive Screener criterion, 2 = significantly different from 2 positive Screener criteria, 3 = significantly different from 3 positive Screener criteria, 4 = significantly different from 4 or 5 positive Screener criteria. All pairwise p values significant at $p < 0.001$ (using Tukey's adjustment for multiple comparisons) and adjusted for age, gender, race/ethnicity, and insurance status

SE standard error of the mean

Health Care Expenses

Children without any special health care needs had an annual mean of $804 in health care expenses, with mean inpatient facility/physician expenses $191, outpatient facility/physician expenses $43, and ED facility/physician expenses $84 annually (Table 3). An increasing trend in expenses was seen for increasing number of qualifying Screener criteria. Mean expenses for CMC were $11,388 total, $3,308 for inpatient, $616 for outpatient, and $221 for ED. Other significant cost drivers for CMC included home health ($2,957) and prescriptions ($2,182). There was significant variation of costs by age. CMC ≤1 year totaled $54,417 ($49,523 inpatient) while CMC 13–17 years totaled $8,566 ($664 inpatient, $2,911 home health, $1,845 prescription medications). Overall, CMC total expenses were 14.2 times that of healthy children, inpatient expenses were 17.3 times, outpatient expenses were 14.3 times, and ED expenses 2.6 times that of healthy children.

Reasons for Encounters

For inpatient encounters, the top three most frequent CCS groups for healthy children were pneumonia (5.2 %), appendicitis (4.6 %), and intestinal infection (4.2 %), while for CMC, the most frequent groups were pulmonary/heart disease (17.5 %), lower respiratory disease (15.6 %), and cardiac/circulatory congenital anomalies (15.0 %). For outpatient encounters (Table 4), the top three groups of CCS for healthy children were other upper respiratory infections (9.5 %), otitis media and related conditions (6.8 %), and other upper respiratory disease (2.7 %), whereas for CMC, the top three were disorders usually diagnosed in infancy, childhood, or adolescence (includes tics, elimination disorders, and pervasive developmental disorder) (23.4 %), attention-deficit and related disorders (18.5 %), and mood disorders (5.5 %). For ED encounters, the top three CCS groups for health children were upper respiratory infections (7.3 %), open wounds of head, neck, and trunk (6.7 %), and fracture of upper limb (6.3 %), whereas for CMC, the top three were pneumonia (7.5 %), epilepsy/convulsions (6.9 %), and other injuries and conditions due to external causes (5.8 %).

Family Satisfaction

Families reported progressively declining measures of satisfaction with health care experiences as medical complexity increased (Table 5). On a scale of 1–4, caregivers of children with no special health care needs rated a mean of 3.71 when asked if "child's doctor listens to you," compared to 3.54 for CMC. Similar declines in satisfaction were found for child's doctor "explains things easily,"

Table 4 Most frequent outpatient diagnosis by number of positive responses to CSHCN Screener

No of CSHCN Screener Criteria	Clinical Classification Software Code	Raw count	% weighted (SE)
0	Other upper respiratory infections	6,260	9.5 (0.3)
	Otitis media and related conditions	3,920	6.8 (0.4)
	Other upper respiratory disease	2,156	2.7 (0.3)
1	Other upper respiratory disease	1,479	10.3 (1.8)
	Other upper respiratory infections	1,082	8.0 (0.6)
	Asthma	999	5.2 (0.7)
2	Attention-deficit, conduct, and disruptive behavior disorder	1,485	16.0 (2.4)
	Other upper respiratory disease	855	8.2 (2.0)
	Asthma	685	6.0 (1.3)
3	Attention-deficit, conduct, and disruptive behavior disorder	1,614	18.9 (2.4)
	Mood disorders	685	10.9 (3.3)
	Disorders usually diagnosed in infancy, childhood, or adolescence	368	10.2 (6.7)
4–5	Attention-deficit, conduct, and disruptive behavior disorder	2,073	18.5 (3.1)
	Disorders usually diagnosed in infancy, childhood, or adolescence	1,750	23.4 (7.0)
	Mood disorders	610	5.5 (1.4)

SE standard error of the percentage

"shows respect," and "spends enough time with you" (all $p < 0.05$ in pairwise comparisons). Mean overall satisfaction with care was 8.93 out of 10 for children without any special needs, 8.85 for children who met one criterion, and declining to 8.37 for CMC ($p < 0.05$).

Discussion

Using responses to the CSHCN Screener to construct a hierarchical proxy for increasing medical complexity, we found that children with the highest level of complexity had an average of 8.7 times more inpatient visits, 7.3 times more outpatient visits, and 2.4 times more ED visits, compared to children without any special health care needs. Overall, CMC total expenses were 14.2 times, inpatient expenses were 17.3 times, outpatient expenses were 14.3 times, and ED expenses 2.6 times greater than that of healthy children. Our findings describe a higher risk of hospitalization for many CMC, but we also found a mean of 19 outpatient visits to a physician per year, or an average of between one and two visits per month.

For children with the highest number of qualifying CSHCN Screener items and high resource use, inpatient

Table 5 Patient satisfaction by number of positive responses to CSHCN Screener

	Number of CSHCN Screener Criteria				
	0	1	2	3	4/5
Child's doctor listens to you					
Mean (SE)	3.71 (0.003)	3.70 (0.01)	3.68 (0.01)	3.62 (0.01)	3.54 (0.01)
Pairwise p values[#]	2, 3, 4	3, 4	3, 4	0, 1, 2, 4	0, 1, 2, 3
Child's doctor explains things easily					
Mean (SE)	3.73 (0.002)	3.73 (0.01)	3.70 (0.01)	3.70 (0.01)	3.59 (0.01)
Pairwise p values[#]	2, 3, 4	2, 3, 4	0, 1, 4	0, 1, 4	0, 1, 2, 3
Child's doctor shows respect					
Mean (SE)	3.75 (0.002)	3.72 (0.01)	3.71 (0.01)	3.65 (0.01)	3.62 (0.01)
Pairwise p values[#]	1, 2, 3, 4	0, 3, 4	0, 3, 4	0, 1, 2	0, 1, 2
Child's doctor spends enough time with you					
Mean (SE)	3.64 (0.003)	3.63 (0.01)	3.63 (0.01)	3.55 (0.01)	3.48 (0.01)
Pairwise p values[#]	3, 4	3, 4	3, 4	0, 1, 2, 4	0, 1, 2, 3
Rating of child's health care prior 12 months, 0–10 scale					
Mean (SE)	8.93 (0.01)	8.85 (0.01)	8.71 (0.02)	8.41 (0.03)	8.37 (0.03)
Pairwise p values[#]	1, 2, 3, 4	0, 2, 3, 4	0, 1, 3, 4	0, 1, 2	0, 1, 2

[#] For pairwise p value, 0 = significantly different from 0 positive Screener criteria, 1 = significantly different from 1 positive Screener criterion, 2 = significantly different from 2 positive Screener criteria, 3 = significantly different from 3 positive Screener criteria, 4 = significantly different from 4 or 5 positive Screener criteria. All pairwise p values significant at $p < 0.05$ (using Tukey's adjustment for multiple comparisons) and adjusted for age, gender, race/ethnicity, and insurance status

SE standard error of the mean

visits appear to be driven by respiratory conditions. This finding from a national data set is consistent with past literature examining clinical programs focusing on CMC [21]. We found, however that behavioral and mental health concerns were associated with many CMC outpatient encounters. We cannot tell whether a particular reason for a visit provided by the caregiver was the primary reason for that visit. However, it is notable that for children who were healthy and for CSHCN with the least medical complexity, over 10 % of outpatient visits were associated with upper respiratory infection. For CMC, only 1.8 % of visits were associated with upper respiratory infection (data not shown in table). Prior literature describe many CMC having neuro-developmental difficulties [22, 23]. Our results show that many of the highest resource utilizers likely have neuropsychiatric needs.

Inpatient expenses for all CMC were 29.0 % of total expenses and ED visits were 1.9 % of total expenses. Home health (26.0 %) and prescriptions (19.2 %) were also significant contributors. For 13–17 year olds in the CMC group, the percentages were 7.7 % inpatient, 2.8 % ED, 34.0 % home health, and 21.5 % prescriptions. These findings suggest that the largest proportion of expenses for the highest pediatric resource utilizers are for supportive care, likely relating to neuropsychiatric issues, and not acute illnesses. The proportion of expenses directed towards supportive care increases as children reach school age and adolescence.

Our findings differ from previous studies suggesting the majority of costs for CMC are accrued in the inpatient side. We identified CMC through a non-validated survey-based method to define complexity, but this methodology has identified high resource use and variation in expenditures [18, 19]. Other studies utilized administrative data, identifying CMC through diagnostic codes that do not reflect true medical care need. Future research needs to examine the optimal method of identifying high resource utilizers and CMC prospectively. A combination of administrative and survey data may be needed to raise the sensitivity and specificity of a predictive algorithm compared to a gold standard of clinical assessment and chart review.

CMC typically require multiple specialists, an array of community-based services, and comprehensive care management and oversight. This care oversight may be delivered by a primary care-based Medical Home, a tertiary care center-based comprehensive care service, or both under a co-management agreement [3, 24]. Interventions to reduce the cost and family burdens of CMC may include enhancing care coordination [25], improving transitions from hospital to home [5], and enrolling CMC into hospital-based comprehensive care services [24]. The latter approach has resulted in some success reducing hospitalizations and overall costs

[11–13, 21]. However, CMC in our national data set averaged fewer than one hospitalization per year, limiting the impact of reducing hospitalizations. The exception is CMC ≤1 year, whose costs may be driven by a neonatal intensive care unit stay. In contrast, we found frequent encounters with the outpatient care system—a mean of 19 annually—driven by neuropsychiatric health needs, although the lack of universal child mental health services means that our findings may represent an underestimate of actual need. Neuropsychiatric needs may also drive the lower perceived quality of care and satisfaction for families of CMC, as families of CSHCN with mental health disorders tend to have higher needs [26, 27]. Higher needs require increased navigation of services, which is cited as the predominant concern for most families of CSHCN [28]. Care coordination and integration of outpatient services may represent an important opportunity to address health care utilization and family needs of CMC.

The potential cost savings that can be realized from improved outpatient care coordination and integration is not well understood. A prior study found that the number of outpatient visits rose even as cost savings were realized through reduced hospitalizations for CMC [11]. The Patient-Centered Medical Home (PCMH) emphasizes care coordination and care management to assist with self-management and outpatient care planning [29]. Intensive outpatient strategies within a PCMH could address important causes of excess CMC health care use, such as reducing respiratory illnesses through timely immunization and use of airway clearance mechanisms. The few hospitalizations found in this study, though, suggest fewer opportunities to reduce costs through preventing hospitalizations. Pharmacy costs, a significant driver, may also be less mutable, and home health may be desirable expenses to reduce inpatient costs. However, health care delivery in the primary care setting has neglected integration of mental health services, despite evidence for improved health and functioning outcomes [30, 31]. Streamlined supportive services, including home health, therapies and prescription medications, may reduce inefficiencies and improve timely access to mental health, with the goal to reduce mental health crises.

Strengths of this study include the use of a national data set. We used two different methods of defining medical complexity with similar results. The results are parent-reported instead of administrative data, reflecting family needs and views. A number of weaknesses should also be accounted for. We did not review any hospital or administrative data. Diagnoses and reasons for visits may not represent the primary reason for the encounters. MEPS data are weighted for nationally representative results, but non-responders could still influence the results. There is no clinical validation of either of the definitions used in this

study for medical complexity as clinically recognized, and the Screener is not designed to identify CMC at the local level. Other methods of defining medical complexity have used ICD-9 codes [32], clinical risk models using administrative data [33], number of specialists seen [21], or a combination of factors [4], and the health care resource patterns may differ among the different definitions. Our methodology characterized 1.9 % of children as having medical complexity, which is higher than previously cited <1 %. Accordingly, our findings may include a group of children who have high expense but lower medical care needs, reflected in increased outpatient resource use relative to prior literature. Finally, our methodology may have resulted in a tautology in which qualifying on increased Screener criteria, including treatment/counseling for a developmental/behavioral problem, may have resulted in a subset which inherently requires more mental health services. However, the 4/5 Screener group was the highest-cost group of children overall, making the group of interest to payers and systems, and our utilization profile was similar to a prior study of technology-dependent children [14].

Conclusion

Children with the highest level of medical complexity and cost have a much higher risk of inpatient, outpatient, and ED encounters and lower parent-rated quality of care. Outpatient encounters may be driven predominantly by mental and behavioral health. System integration reforms should focus on integration of community-based services providing appropriate levels of proactive preventive care, inclusive of mental and behavioral health.

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