Increasing Prevalence of Medically Complex Children in US Hospitals

WHAT'S KNOWN ON THIS SUBJECT: Little is known about the hospitalization rates of medically complex children.

WHAT THIS STUDY ADDS: A significant increase in the number of medically complex children over a 15-year period was documented in this study.

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KEY WORDS

children with special health care needs, medically complex children, chronic illness, complex chronic conditions, cerebral palsy, bronchopulmonary dysplasia

ABBREVIATIONS

CP—cerebral palsy
BPD—bronchopulmonary dysplasia
CCC—complex chronic condition
NIS—Nationwide Inpatient Sample
HCUP—Healthcare Costs and Utilization Project
ICD-9—*International Classification of Diseases, Ninth Revision*

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abstract

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OBJECTIVE: In this study we used national data to determine changes in the prevalence of hospital admissions for medically complex children over a 15-year period.

PATIENTS AND METHODS: Data from the Nationwide Inpatient Sample, a component of the Healthcare Cost and Utilization Project, was analyzed in 3-year increments from 1991 to 2005 to determine national trends in rates of hospitalization of children aged 8 days to 4 years with chronic conditions. Discharge diagnoses from the Nationwide Inpatient Sample were grouped into 9 categories of complex chronic conditions (CCCs). Hospitalization rates for each of the 9 CCC categories were studied both individually and in combination. Trends of children hospitalized with 2 specific disorders, cerebral palsy (CP) and bronchopulmonary dysplasia, with additional diagnoses in more than 1 CCC category were also examined.

RESULTS: Hospitalization rates of children with diagnoses in more than 1 CCC category increased from 83.7 per 100 000 (1991–1993) to 166 per 100 000 (2003–2005) (P[r] $<$ .001). The hospitalization rate of children with CP plus more than 1 CCC diagnosis increased from 7.1 to 10.4 per 100 000 ($P = .002$), whereas the hospitalization rates of children with bronchopulmonary dysplasia plus more than 1 CCC diagnosis increased from 9.8 to 23.9 per 100 000 ($P < .001$).

CONCLUSIONS: Consistent increases in hospitalization rates were noted among children with diagnoses in multiple CCC categories, whereas hospitalization rates of children with CP alone have remained stable. The relative medical complexity of hospitalized pediatric patients has increased over the past 15 years. *Pediatrics* 2010;126:638–646

Children with special health care needs "are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[1] Among this group are a smaller number of medically complex, or medically fragile, children including those with intense medical needs that result from multisystem disease states, technology dependence, or complex medication regimens.[2] Although generally thought to be increasing in number, we are aware of no data that have shown an increasing prevalence of medically complex children in US hospitals.

Advances in neonatal and critical care, as well as general medical and nutritional care, have resulted in improvements in the survival rate of fragile infants, who are often left with complex systemic health problems. Improvements in neonatal intensive care, including advances in surfactant therapy and resuscitation protocols, have resulted in an improved survival rate of very low birth weight neonates.[3,4] Newer developments in infant and child nutrition, including increased use of gastrostomy tubes, have improved the survival rate of children with cerebral palsy (CP).[5–13] Surgical advances have resulted in an improved survival rate for infants with certain congenital defects including diaphragmatic hernia, abdominal wall defects, esophageal atresia, and cyanotic heart defects.[14–18] Many of these children have systemic health problems including neurodevelopmental disabilities, gastrointestinal illnesses, pulmonary complications, musculoskeletal abnormalities, and nutritional deficits.[5–7,13,19,20] These conditions may require frequent hospital and subspecialty care.[21,22]

Trends in the incidence of and mortality from many specific conditions that would contribute to medical complexity (eg, CP, chronic lung disease, mental retardation, hydrocephalus, and congenital birth defects) show the occurrence of these individual conditions to be fairly stable over the recent past.[5–7,12,13,23–26] On the other hand, some disorders have certainly increased in frequency. Gastroschisis is a condition with increasing prevalence over time that certainly contributes to medical complexity.[27,28] However, the number of folate-sensitive birth defects, which also contribute to medical complexity, has decreased.[23,26,29]

Although individual conditions do not seem to be significantly increasing in incidence, the complexity of the case mix, especially among hospitalized children, may be increasing. The purpose of this study was to use national data to examine trends in hospitalization rates for medically complex children over a 15-year period from 1991 to 2005. Two related definitions of medically complex children were used to define our cohorts in parallel analyses. The first consisted of children with diagnoses in more than 1 chronic-condition category,[30–32] defined by organ system, without requiring the presence of any single specific condition. The second consisted of children with a single specific diagnosis, CP or bronchopulmonary dysplasia (BPD), and the presence of a diagnosis in 1 of the chronic-condition categories. The presence of multiple chronic conditions was chosen for this study because children with these combinations of conditions are more likely to require care coordination and the involvement of multiple subspecialists. CP and BPD were chosen as sample individual diagnoses from the list of complex chronic conditions (CCC) because they represent relatively common diagnoses with frequent comorbidities. The incidence of both CP and BPD, which also includes chronic lung disease, have been well studied and, thus, are available for comparison.[4–7,12,13,33–37]

METHODS

Databases

We used the Nationwide Inpatient Sample (NIS) for these analyses. The NIS is a large nationally representative hospital discharge database created by the Agency for Healthcare Research and Quality as part of the Healthcare Costs and Utilization Project (HCUP). HCUP databases were developed through a federal-state-industry partnership and contain admission-level information compiled in a uniform format with privacy protections in place (Agency for Healthcare Research and Quality, 2007). These databases enable research on a broad range of health care services and health policy issues at the national, state, and local market levels.

The NIS was designed to approximate a 20% stratified random sample of all US hospitals (defined as short-term, nonfederal, general, and specialty hospitals including teaching and children's hospitals) from states that contribute their state inpatient databases to the HCUP. The NIS includes 100% of discharges from each sampled hospital. It contains data from ~1000 hospitals and includes 7 to 8 million hospital discharges annually. The Agency for Healthcare Research and Quality has developed appropriately scaled discharge weights to generate national estimates of hospitalizations from the NIS. With these weights, national estimates of hospitalizations and hospitalization rates are comparable across years despite the varying number of states participating in each year of the HCUP (Agency for Healthcare Research and Quality, 2007).[38] The NIS's large sample size enables analyses of rare conditions such as congenital anomalies, uncommon treatments such as

organ transplantation, and special patient populations such as the uninsured. For this analysis, we used NIS data from the years 1991 through 2005.

Case Selection

Feudtner et al[30] constructed a scheme of CCCs based on the definition of any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or 1 organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center. This definition was used to construct a list of possible conditions based on *International Classification of Diseases, Ninth Revision* (ICD-9) codes. The 9 large CCC categories, specific diagnoses included, and current ICD-9 codes are listed in the Appendix.

Statistical Analyses

Hospitalization rates for children in each of the 9 categories were studied individually. We first examined hospitalization trends for children with a diagnosis of a single CCC and also for children with diagnoses in more than 1 CCC category. We then analyzed hospitalization rates for children with CP and BPD individually and then evaluated hospitalization rates of children with each of these diagnoses plus at least 1 or more CCC diagnoses. CP and BPD were chosen because both are chronic conditions that occur frequently alone and are recognized to complicate the management of children when present in combination with other conditions. The ICD-9 codes used include 343.0–343.9 for CP and 770.7 for BPD.

Numerators for all rate calculations were weighted national estimates of hospitalizations for children we defined as medically complex from 8 days through 4 years of age for a given year. These ages were chosen in an attempt to exclude primary admissions to neonatal units and to document survivors after the neonatal period. Denominators were census-based estimations of the number of children in the United States between 0 and 4 years of age for a given year. Logistic regression models were used to test for linear trend over time. All models were adjusted for available demographic variables, which included race/ethnicity, gender, age (in years), insurance status, high versus low zip code median income, and region of the country. Race data were missing for ~25% of cases in NIS data. Missing race was included in the regression models as an indicator variable. Stata 10 MP statistical software (Stata Corp, College Station, TX) was used for all analyses.

RESULTS

The total number of hospitalizations for children aged 8 days to 4 years over the 15 years of the study was 61 065 669 weighted (95% confidence interval: 60 096 115–62 035 223), of which 2 828 315 (95% confidence interval: 2 665 137–2 991 493) met our definition of medically complex.

The hospitalization rates for children with diagnoses in a single CCC category are shown in Table 1 for 3-year intervals from 1991 to 2005. Hospitalization rates for children with diagnoses in the following individual categories increased significantly between 1991 and 1993 and 2003 and 2005: cardiovascular, respiratory, renal, metabolic, and other. Hospitalization rates for children with a diagnosis in the hematologic/immunologic category decreased between 1991 and 1993 and 2003 and 2005. Hospitalization rates for children in the other 3 CCC categories (neuromuscular, gastrointestinal, and malignancy) remained relatively stable.

Hospitalization rates for children with diagnoses in more than 1 CCC category are shown in Table 2 for 3-year intervals from 1991 to 2005. Rates increased significantly for all combinations of CCC categories at the $P < .001$ level. The largest percentage increase was among children with a diagnosis in the renal CCC category plus at least 1 other CCC (28.1% increase per year-group; $P < .001$). The smallest percentage increase was among children with a diagnosis in the neuromuscular CCC category plus at least 1 other CCC (14.8% increase per year-group; $P < .001$).

The prevalence over time of hospitalizations of children with diagnoses in any 1 CCC category and more than 1 CCC category are shown in Fig 1. The hospitalization rates of children with diagnoses in a single CCC category increased by an average of 5.59% each

TABLE 1 Hospitalization Rates per 100 000 Children for CCC Categories, Isolated in Terms of No Comorbid Diagnoses From Another CCC Category

CCC Category	1991–1993	1994–1996	1997–1999	2000–2002	2003–2005	% Change/ Year-Group	*P*
Neuromuscular	121	119	111	109	112	−1.7	.484
Cardiovascular	184	206	216	251	291	11.7	<.001
Respiratory	79	85	84	89	98	5.8	.019
Renal	33	38	42	48	56	13.9	<.001
Gastrointestinal	29	30	29	30	31	1.7	.579
Hematologic/ immunologic	93	103	92	82	79	−6.9	.005
Metabolic	22	25	26	30	34	11.0	<.001
Other	70	77	82	92	107	11.6	<.001
Malignancy	135	136	134	136	139	2.3	.536

Rates were adjusted for gender, race, median income of zip code, insurance status, and region of country.

TABLE 2 Hospitalizations Rates per 100 000 Children for CCC Categories With at Least 1 Comorbid Diagnosis From Another CCC Category

CCC Category	1991–1993	1994–1996	1997–1999	2000–2002	2003–2005	% Change/ Year-Group	*P*
Neuromuscular	21	25	27	31	37	14.8	<.001
Cardiovascular	50	61	70	84	105	18.6	<.001
Respiratory	20	26	31	38	50	22.9	<.001
Renal	8	10	12	17	23	28.1	<.001
Gastrointestinal	11	12	14	16	19	15.4	<.001
Hematologic/ immunologic	7	8	10	11	14	17.2	<.001
Metabolic	5	7	8	10	13	23.8	<.001
Other	5	5	6	7	9	16.7	<.001
Malignancy	8	10	11	13	15	17.4	<.001

Rates were adjusted for gender, race, median income of zip code, insurance status, and region of country. The categories are not mutually exclusive.

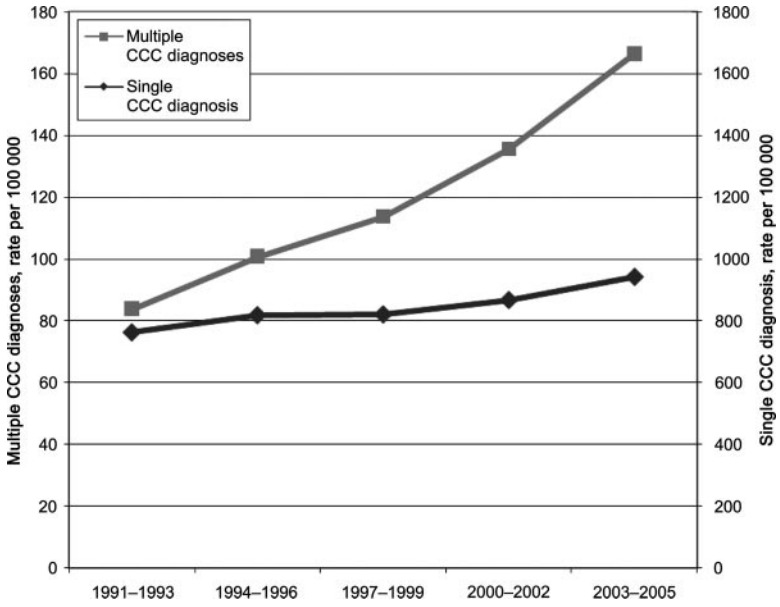

FIGURE 1
Hospitalization rates of children diagnosed with a single CCC and children diagnosed with more than 1 CCC. Hospitalization rates were adjusted for race, ethnicity, gender, insurance status, median income of zip code, and region of the country. The change in hospitalization rate for children with a single CCC diagnosis was 5.59% per year-group ($P < .05$), and the change in hospitalization rate for children with more than 1 CCC diagnoses was 17.6% per year-group ($P < .001$).

year-group from 763.7 per 100 000 to 943.2 per 100 000 ($P = .022$). The hospitalization rates of children with diagnoses in more than 1 CCC category increased by an average of 17.6% each year-group and doubled from 83.7 per 100 000 in 1991–1993 to 166.3 per 100 000 in 2003–2005 ($P < .001$).

The hospitalization rate of children with CP only and with CP plus 1 or more diagnoses in a CCC category are shown in Fig 2. The hospitalization rates of children with CP alone decreased 4.02% per year-group ($P = .10$), from 53 per 100 000 in 1991–1993 to 45 per 100 000 in 2003–2005. The hospitalization rates of children with CP plus at least 1 comorbid CCC diagnosis increased 10.41% per year-group ($P = .002$), from 7.1 per 100 000 in 1991–1993 to 10.4 per 100 000 in 2003–2005.

The hospitalization rates of children with BPD alone and BPD plus a diagnosis in 1 or more CCC categories are reported in Fig 3. The hospitalization rate of children with BPD alone increased 7.07% per year-group ($P = .009$), from 38 per 100 000 to 52.3 per 100 000. The hospitalization rate of children with BPD plus at least 1 comorbid CCC diagnosis increased 22.5% per year-group ($P < .001$), from 9.8 per 100 000 in 1991–1993 to 23.9 per 100 000 in 2003–2005.

DISCUSSION

Using the NIS database, a sample of hospitalizations that generalizes to the US population, we found that the rates of hospital admission for medically complex children aged 8 days to 4 years increased significantly from 1991 to 2005. The hospitalization rates of children with diagnoses in individual CCC categories increased for children with cardiovascular disease, respiratory disease, renal disease, metabolic disorders, and other congenital defects/genetic disorders while either remaining stable or decreasing for all other CCC categories. The hospitalization rates of children with diagnoses in multiple CCC categories increased for all category combinations.

The prevalence of CP has been shown to be stable over the past 20 to 30 years, although possibly decreasing slightly in the late 1990s, and the incidence of postneonatally acquired CP seems to have decreased.[5–7,12,13,26] Our results would support the conclusion that the rate of CP alone has remained stable over the 15 years of this study. The hospitalization rates of children with CP plus at least 1 comorbid diagnosis in a CCC category has increased.

A previous study of birth-defect trends had revealed an increase in hospitalizations of children with congenital cardiovascular defects and genitourinary defects between 1997 and 2004 only when in combination with other diagnoses and an increase in digestive

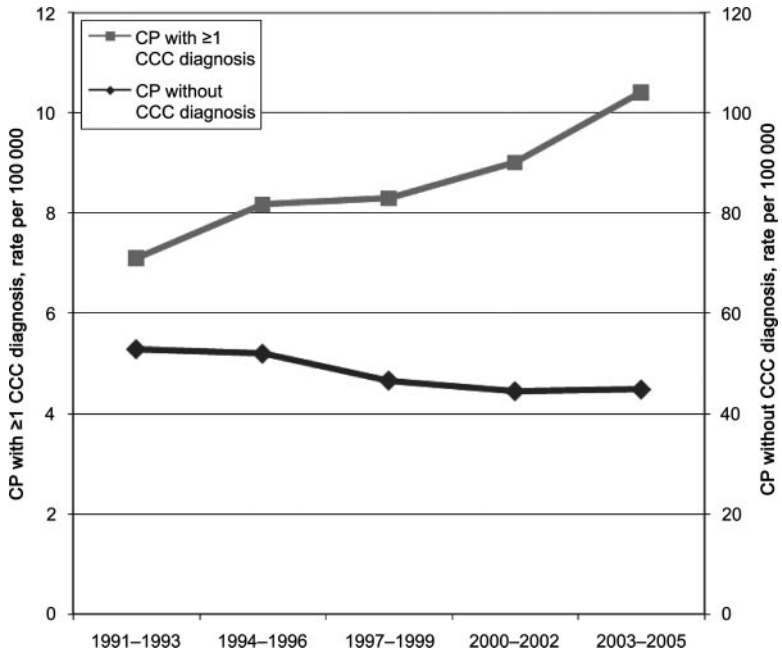

FIGURE 2

Hospitalization rates of children with a CP diagnosis without a comorbid CCC diagnosis and of children with a CP diagnosis with 1 or more comorbid CCC diagnoses. Hospitalization rates were adjusted for race, ethnicity, gender, insurance status, median income of zip code, and region of the country. The mean percentage change per year-group for CP without CCC diagnosis was −4.02% ($P = .10$), and the mean percentage change per year-group for CP with 1 or more CCC diagnoses was 10.41% ($P < .01$).

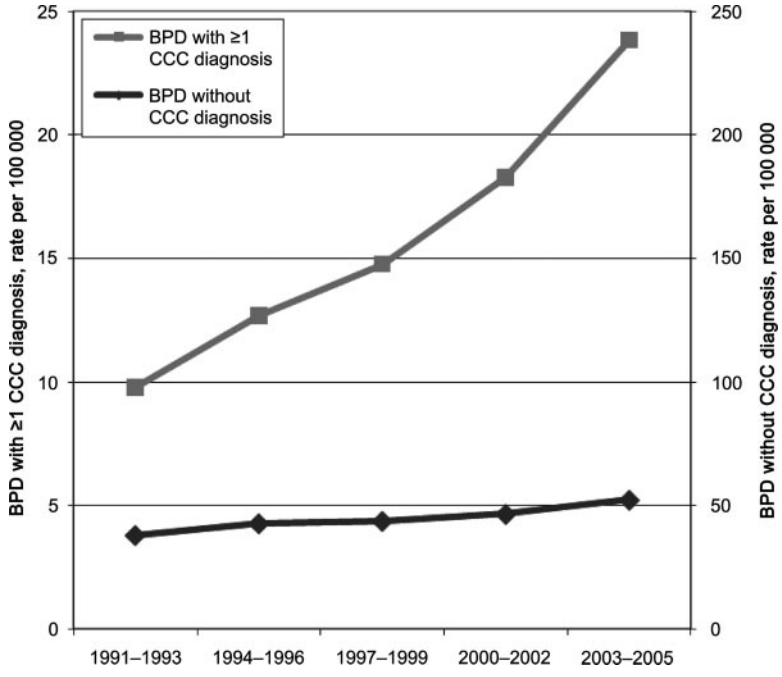

FIGURE 3

Hospitalization rates of children with BPD without a comorbid CCC diagnosis and of children with BPD with 1 or more comorbid CCC diagnoses. Hospitalization rates were adjusted for race, ethnicity, gender, insurance status, median income of zip code, and region of the country. The mean percentage change per year-group for all children with BPD diagnosis without CCC diagnosis was 7.07% ($P < .01$), and the mean percentage change per year-group for all children with BPD diagnosis with 1 or more CCC diagnoses was 22.5% ($P < .001$).

congenital anomalies alone.[39] The number of children with end-stage renal disease increased 5.9% between 2000 and 2006, whereas the number of children on hemodialysis has grown 8.2% since 2000, and 32.7% of patients have a primary diagnosis of cystic/hereditary/congenital diseases.[40] These results support our findings of increases in renal disease, cardiovascular disease, and other congenital defects/genetic disorders.

The exact etiology of the observed increase in rates of hospitalization for children with multiple conditions is unknown at this time. However, it seems likely that a combination of increased survival rates, resulting from lowering mortality rates of these preterm infants and children born with congenital defects, and shorter hospitalizations with increased use of home therapies may explain this increase.

Previous studies have revealed that 35% to 53% of preterm infants with BPD are rehospitalized in the first year of life.[33–35] Prematurity itself increases the risk of hospitalization from ~2.5% in the first year of life for term infants to between 23% and 63% for all preterm infants in the first 2 years of life.[36,37,41] Our results suggest that an increase in hospitalization, or rehospitalization, of children with BPD has occurred during the study years, with an even greater increase in the hospitalization rates of children with BPD plus at least 1 comorbid CCC diagnosis. Increased use of home oxygen therapy during the time of our study may have allowed for earlier discharge of children who previously may have experienced prolonged initial hospitalizations. These infants would be expected to be at risk of more subsequent hospital admissions, which is consistent with other studies documenting that BPD with the presence of other complication conditions, such as those necessitating ventriculoperitoneal

shunt placement, increases risk of readmission.[35]

Our analyses have several limitations. Although we believe our definition of medical complexity is robust and well suited to the aims of the study, it does restrict our analysis to a subpopulation of children who are defined as medically complex exclusively on the basis of ICD-9 diagnostic codes. We did not include procedure codes associated with medical complexity or codes related to technology dependence or use of technology at the home. A similar analysis with a different definition of medical complexity may yield complementary results. In addition, our analysis included only inpatient treatment. We did not address outpatient utilization of services. Analysis was also limited to admissions between 8 days and 4 years of age. The analyses were based on ICD-9 Clinical Modification codes from hospital discharge summaries that were primarily collected for reimbursement purposes, not research. Coding practices can vary according to geographical region, individual hospital, and over time while being subject to error at multiple steps. For example, CP may not be formally diagnosed in particularly young hospitalized children, or it may be a complicating condition that did not require specific treatment during the hospitalization and, thus, was not coded. However, many of these codes are for diagnoses that are serious and would likely not be excluded because of severity. Although previous studies have revealed some agreement between ICD-9 codes and chronic medical conditions including CCCs, there may be some discordance between coding and clinical assessments that likely varies across different chronic conditions.[42] ICD-9 codes have also been documented to appropriately identify children with chronic medical conditions.[43]

The NIS does not have unique patient identifiers to allow for tracking of individuals across hospitalizations, which leads to some individual children being counted multiple times in our analysis. However, the increases we documented still represent an increase in utilization of resources and a change in the composition of hospital census. The HCUP has been used to document burden to systems such as emergency department utilization,[44] another context in which a single individual may have multiple visits, which increases the burden to the health care system. It has also been used to confirm trends in diseases (ie, survival after coronary artery bypass surgery) documented by using other methodologies.[45] The HCUP databases have also been used to document trends in specific conditions such as folate-sensitive birth defects and general birth defects.[23] Our study did not address length of hospitalization. Finally, it must be acknowledged that a child may have a single disease process of a severity great enough to qualify as medically complex or multiple disease processes of mild severity. Disease severity is not available through this data set.

Our analyses have several strengths. We used a specific definition that is more likely to include only children who would be considered to be very medically complex. We also used a nationwide sample with data collected over 15 years from a large number of hospitals and a large number of patients. Our findings, therefore, represent the entire country.

Appropriate care coordination has been shown to decrease hospitalization rates of children with complex health conditions.[46] Applying a medical home model to the inpatient setting with coordination and communication between hospital caregivers, primary care providers, and specialists is challenging but has been suggested as beneficial to the child, the hospital, and caregivers.[47,48] Additional research should confirm the value of a hospital-based medical home.

In an era of increasingly stringent criteria for inpatient admissions, the increase in hospitalization rates of children with complex chronic conditions is remarkable. A previous study revealed decreases in total hospitalization rates for children aged 0 to 17 years from 1991 to 1998.[49] This decrease was found to be less for children with chronic conditions than non–chronically ill children. It is possible that improved or increased utilization of certain codes may have contributed to these increases. However, the diagnoses addressed in this study are major conditions that would not typically be omitted from any chart or billing record at any time period.

These data, in conjunction with the limitations discussed above, point to a need for improved tracking of children with special health care needs to better understand the patients and their health care and care-coordination needs. These data also support improving resident education in the care of these children both acutely and in their communities.

CONCLUSIONS

When using a limited and specific definition of medical complexity, hospitalization rates of children with multiple CCCs were found to be increasing. Hospitals that care for these challenging children should consider clinical and training programs focused on this increasing proportion of their inpatient population.

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APPENDIX Classification Scheme of CCCs

CCC Category and Included Diagnoses	ICD-9 Code
Neuromuscular malformation	
Brain and spinal cord	740.0–742.9
Mental retardation	318.0–318.2
Central nervous system degeneration and disease	330.0–330.9, 334.0–334.2, 335.0–335.9
Infantile CP	343.0–343.9
Muscular dystrophies and myopathies	359.0–359.3
Cardiovascular malformation	
Heart and great vessel	745.0–747.4
Cardiomyopathies	425.0–425.5, 429.1
Conduction disorders	426.0–427.4
Dysrhythmias	427.6–427.9
Respiratory	
Respiratory malformations	748.0–748.9
Chronic respiratory disease	770.7
Cystic fibrosis	277.0
Renal	
Congenital anomalies	753.0–753.9
Chronic renal failure	585
Gastrointestinal	
Congenital anomalies	750.3, 751.1–751.3 751.6–751.9
Chronic liver disease and cirrhosis	571.4–571.9
Inflammatory bowel disease	555.0–556.9
Hematologic or immunologic	
Sickle cell disease	282.5–282.6
Hereditary anemias	282.0–282.4
Hereditary immunodeficiency	279.00–279.9, 288.1–288.2, 466.1
Acquired immunodeficiency	042
Metabolic	
Amino acid metabolism	270.0–270.9
Carbohydrate metabolism	271.0–271.9
Lipid metabolism	272.0–272.9
Storage disorders	277.3–277.5
Other metabolic disorders	275.0–275.3, 277.2, 277.4, 277.6, 277.8–277.9
Other congenital or genetic defect	
Chromosomal anomalies	758.0–758.9
Bone and joint anomalies	259.4, 737.3, 756.0–756.5
Diaphragm and abdominal wall	553.3, 756.6–756.7
Other congenital anomalies	759.7–759.9
Malignancy	
Malignant neoplasms	140.0–208.9, 235.0–239.9

These are the CCC categories, included diagnoses, and current ICD-9 codes from the 2000 Feudtner et al[50] article.

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