

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.

abstract

FREE

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

AUTHORS: Katherine H. Burns, MD, Patrick H. Casey, MD, Robert E. Lyle, MD, T. Mac Bird, MS, Jill J. Fussell, MD, and James M. Robbins, PhD

Department of Pediatrics, College of Medicine, University of Arkansas for Medical Sciences and Arkansas Children's Hospital, Little Rock, Arkansas

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*

www.pediatrics.org/cgi/doi/10.1542/peds.2009-1658

doi:10.1542/peds.2009-1658

Accepted for publication Jun 1, 2010

Address correspondence to Katherine H. Burns, MD, Department of Pediatrics, University of Arkansas for Medical Sciences, 1 Children's Way, Slot 512-41, Little Rock, AR 72202. E-mail: burnskatherinel@uams.edu

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2010 by the American Academy of Pediatrics

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

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.^{25,26,29}

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, non-federal, 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 al³⁰ 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

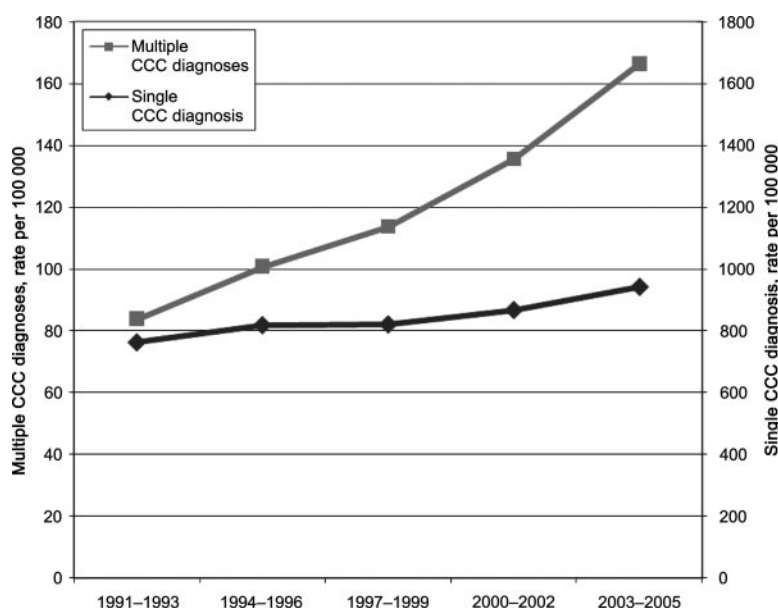
| CCC Category | 1991–1993 | 1994–1996 | 1997–1999 | 2000–2002 | 2003–2005 | % Change/ Year-Group | P |
|-----------------------------|-----------|-----------|-----------|-----------|-----------|-------------------------|-------|
| Neuromuscular | 121 | 119 | 111 | 109 | 112 | –1.7 | .484 |
| Cardiovascular | 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 | <i>P</i> |
|-----------------------------|-----------|-----------|-----------|-----------|-----------|-------------------------|----------|
| 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

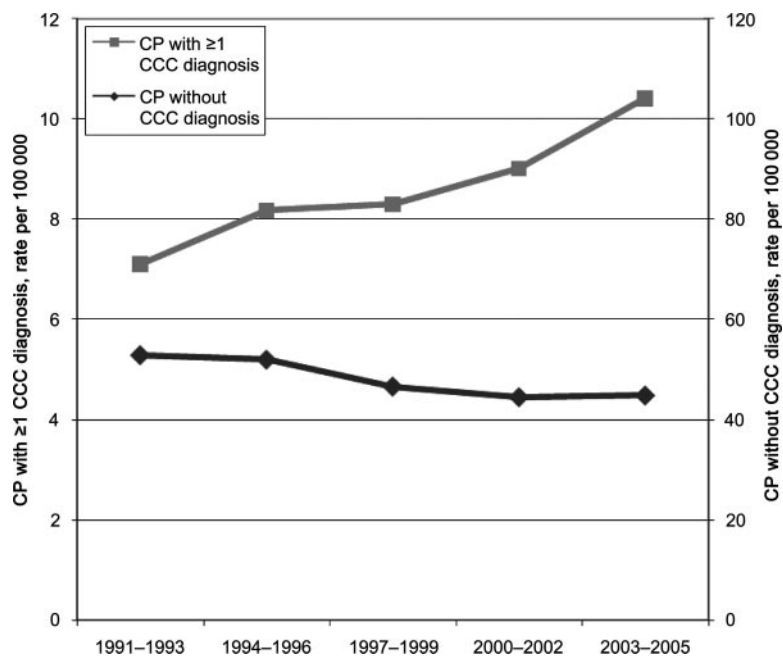


FIGURE 2

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% ($P < .01$).

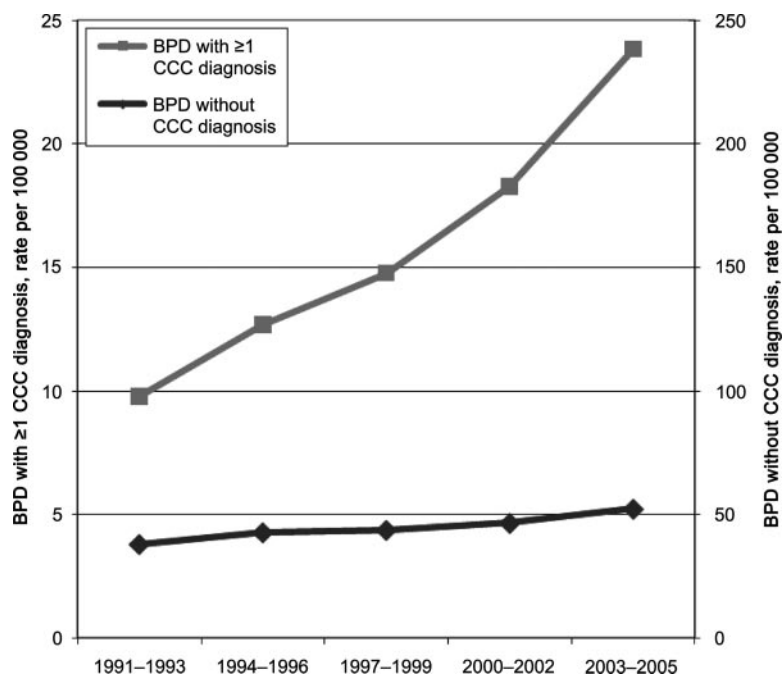


FIGURE 3

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 $\sim 2.5\%$ 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.⁵⁵

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.

REFERENCES

- McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102(1 pt 1):137–139
- Srivastava R, Stone BL, Murphy NA. Hospitalist care of the medically complex child. *Pediatr Clin North Am*. 2005;52(4):1165–1187
- Kaiser JR, Tilford JM, Simpson PM, Salhab WA, Rosenfeld CR. Hospital survival of very-low-birth-weight neonates from 1977 to 2000. *J Perinatol*. 2004;24(6):343–350
- Robertson CMT, Watt MJ, Yasui Y. Changes in the prevalence of cerebral palsy for children born very prematurely within a population-based program over 30 years. *JAMA*. 2007;297(24):2733–2740
- Odding E, Roebroek ME, Stam HJ. The epidemiology of cerebral palsy: incidence, impairments and risk factors. *Disabil Rehabil*. 2006;28(4):183–191
- Strauss D, Shavelle R, Reynolds R, Rosenbloom L, Day S. Survival in cerebral palsy in the last 20 years: signs of improvement? *Dev Med Child Neurol*. 2007;49(2):86–92
- Reid SM, Lanigan A, Reddihough DS. Post-neonatally acquired cerebral palsy in Victoria, Australia, 1970–1999. *J Paediatr Child Health*. 2006;42(10):606–611
- Sullivan PB, Juszczak E, Bachlet AM, et al. Gastrostomy tube feeding in children with cerebral palsy: a prospective, longitudinal study. *Dev Med Child Neurol*. 2005;47(2):77–85
- Rogers B. Feeding method and health outcomes of children with cerebral palsy. *J Pediatr*. 2004;145(2 suppl):S28–S32
- Fung EB, Samson-Fang L, Stallings VA, et al. Feeding dysfunction is associated with poor growth and health status in children with cerebral palsy. *J Am Diet Assoc*. 2002;102(3):361–368
- Samson-Fang L, Fung EB, Stallings VA, et al. Relationship of nutritional status to health and societal participation in children with cerebral palsy. *J Pediatr*. 2002;141(5):637–643
- Vincer MJ, Allen AC, Joseph K, Stinson DA, Scott H, Wood E. Increasing prevalence of cerebral palsy among very preterm infants: a population-based study. *Pediatrics*. 2006;118(6). Available at: <http://www.pediatrics.org/cgi/content/full/118/6/e1621>
- Dolk H, Parkes J, Hill N. Trends in the prevalence of cerebral palsy in Northern Ireland, 1981–1997. *Dev Med Child Neurol*. 2006;48(6):406–412
- Gordon BM, Rodriguez S, Lee M, Chang RK. Decreasing number of deaths of infants with hypoplastic left heart syndrome. *J Pediatr*. 2008;153(3):354–358
- Orford J, Cass DT, Glasson MJ. Advances in the treatment of oesophageal atresia over three decades: the 1970s and the 1990s. *Pediatr Surg Int*. 2004;20(6):402–407
- Lally KP, Lally PA, Van Meurs KP, et al; Congenital Diaphragmatic Hernia Study Group. Treatment evolution in high-risk congenital diaphragmatic hernia. *Ann Surg*. 2006;244(4):505–513
- Chiu PPL, Sauer C, Mihailovic A, et al. The price of success in the management of congenital diaphragmatic hernia: is improved survival accompanied by an increase in long-term morbidity? *J Pediatr Surg*. 2006;41(5):888–892
- Salihi HM, Pierre-Louis BJ, Druschel CM, Kirby RS. Omphalocele and gastroschisis in the state of New York, 1992–1999. *Birth Defects Res A Clin Mol Teratol*. 2003;67(9):630–636
- Hack M, Taylor G, Drotar D, et al. Chronic conditions, functional limitations, and special health care needs of school-aged children born with extremely low-birth-weight in the 1990s. *JAMA*. 2005;294(3):318–325
- Farooqi A, Hagglof B, Sedin G, Gothefors L, Serenius F. Chronic conditions, functional limitations, and special health care needs in 10- to 12-year-old children born at 23 to 25 week's gestation in the 1990s: a Swedish national prospective follow-up study. *Pediatrics*. 2006;118(5). Available at: <http://www.pediatrics.org/cgi/content/full/118/5/e1466>
- Chiu PPL, Hedrick HL. Postnatal management and long-term outcome for survivors with congenital diaphragmatic hernia. *Prenat Diagn*. 2008;28(7):592–603
- Chen C, Jeruss S, Chapman JS, et al. Long-term functional impact of congenital diaphragmatic hernia repair on children. *J Pediatr Surg*. 2007;42(4):657–665
- Robbins JM, Tilford JM, Bird T, Cleves MA, Reading A, Hobbs CA. Hospitalizations of newborns with folate-sensitive birth defects before and after fortification of foods with folic acid. *Pediatrics*. 2006;118(3):906–915
- Persson EK, Hagberg G, Uvebrant P. Hydrocephalus prevalence and outcome in a population-based cohort of children born in 1989–1998. *Acta Paediatr*. 2005;94(6):726–732
- Atladóttir HÓ, Parner ET, Schendel D, Dalsgaard S, Thomsen PH, Thorsen P. Time trends in reported diagnoses of childhood neuropsychiatric disorders. *Arch Pediatr Adolesc Med*. 2007;161(2):193–198
- Bhasin TK, Brocksen S, Avchen RN, Braun KV. Prevalence of four developmental disabilities among children aged 8 years: Metropolitan Atlanta Developmental Disabilities Surveillance Program, 1996 and 2000 [published correction appears in *MMWR Morb Mortal Wkly Rep*. 2006;55(4):105–106]. *MMWR Surveill Summ*. 2006;55(1):1–9
- Houglund K, Hanna A, Meyers R, Null D. Increasing prevalence of gastroschisis in Utah. *J Pediatr Surg*. 2005;40(3):535–540
- Alvarez S, Burd R. Increasing prevalence of gastroschisis repairs in the United States: 1996–2003. *J Pediatr Surg*. 2007;42(6):943–946
- Vu LT, Nobuhara KK, Laurent C, Shaw GM. Increasing prevalence of gastroschisis: population-based study in California. *J Pediatr*. 2008;152(6):807–811
- Feudtner C, Christakis D, Connell F. Pediatric deaths attributable to complex chronic conditions: a population-based study of Washington State, 1980–1997. *Pediatrics*. 2000;106(1 pt 2):205–209
- Feudtner C, Feinstein J, Satchell M, Zhao H, Kang T. Shifting place of death among children with chronic complex conditions in the United States, 1989–2003. *JAMA*. 2007;297(24):2725–2732
- Feudtner C, Hays R, Haynes G, Geyer R, Neff J, Koepsell T. Deaths attributed to pediatric complex chronic conditions: national trends and implications for supportive care services. *Pediatrics*. 2001;107(6). Available at: <http://www.pediatrics.org/cgi/content/full/107/6/e99>
- Jeng SF, Hsu CH, Tsao PN, et al. Bronchopulmonary dysplasia predicts adverse developmental and clinical outcomes in very-low-birthweight infants. *Dev Med Child Neurol*. 2008;50(1):51–57
- Ehrenkranz RA, Walsh MC, Vohr BR, et al; National Institutes of Child Health and Human Development Neonatal Research Network. Validation of the National Institutes of Health consensus definition of bronchopulmonary dysplasia. *Pediatrics*. 2005;116(6):1353–1360
- Morris BH, Gard CC, Kennedy K; NICHD Neonatal Research Network. Rehospitalization of extremely low birth weight (ELBW) infants: are there racial/ethnic disparities? *J Perinatol*. 2005;25(10):656–663
- Cunningham CK, McMillan JA, Gross SJ. Rehospitalization for respiratory illness in infants of less than 32 weeks' gestation. *Pediatrics*. 1991;88(3):527–532

37. Smith VC, Zupancic JA, McCormick MC, et al. Rehospitalization in the first year of life among infants with bronchopulmonary dysplasia. *J Pediatr*. 2004;144(6):799–803
38. Holman R, Belay E, Curns A, Schonberger L, Steiner C. Kawasaki syndrome hospitalizations among children in the United States, 1988–1997. *Pediatrics*. 2003;111(2):448
39. Russo CA, Elixhauser A. Healthcare Cost and Utilization Project (HCUP) statistical brief #24: hospitalizations for birth defects, 2004. Available at: <http://www.hcupdoc.net/reports/statbriefs/sb24.jsp>. Accessed May 18, 2009
40. US Renal Data System. *USRDS 2008 Annual Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States—Pediatric ESRD*. 2008 ed. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2008
41. Ehrenkranz RA, Dusick AM, Vohr BR, Wright LL, Wrage LA, Poole K. Growth in the neonatal intensive care unit influences neurodevelopmental and growth outcomes of extremely low birth weight infants. *Pediatrics*. 2006;117(4):1253–1261
42. Ford JB, Roberts CL, Algert GS, Bowen JR, Bajuk B, Henderson-Smart DJ; NICUS group. Using hospital discharge data for determining neonatal morbidity and mortality: a validation study. *BMC Health Serv Res*. 2007;7:188
43. Daley M, Barrow J, Pearson K, et al. Identification and recall of children with chronic medical conditions for influenza vaccination. *Pediatrics*. 2004;113(1 pt 1). Available at: <http://www.pediatrics.org/cgi/content/full/113/1/e26>
44. Schoenfeld E, McKay M. Weekend emergency department visits in Nebraska: higher utilization, lower acuity. *J Emerg Med*. 2010;38(4):542–545
45. Becker E, Rahimi A. Disparities in race/ethnicity and gender in in-hospital mortality rates for coronary artery bypass surgery patients. *J Natl Med Assoc*. 2006;98(11):1729–1739
46. 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
47. Antonelli RC, Antonelli DM. Providing a medical home: the cost of care coordination services in a community-based, general pediatric practice. *Pediatrics*. 2004;113(5 suppl):1522–1528
48. Cohen E, Friedman J, Nicholas DB, Adams S, Rosenbaum P. A home for medically complex children: the role of hospital programs. *J Healthc Qual*. 2008;30(3):7–15
49. Neff J, Valentine J, Park A, et al. Trends in pediatric hospitalizations of children in Washington State by insurance and chronic condition status, 1991–1998. *Arch Pediatr Adolesc Med*. 2002;156(7):703–709

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 al³⁰ article.

Increasing Prevalence of Medically Complex Children in US Hospitals
Katherine H. Burns, Patrick H. Casey, Robert E. Lyle, T. Mac Bird, Jill J. Fussell and
James M. Robbins

Pediatrics; originally published online September 20, 2010;

DOI: [10.1542/peds.2009-1658](https://doi.org/10.1542/peds.2009-1658)

| | |
|---|---|
| Updated Information & Services | including high resolution figures, can be found at: /content/early/2010/09/20/peds.2009-1658 |
| Citations | This article has been cited by 46 HighWire-hosted articles: /content/early/2010/09/20/peds.2009-1658#related-urls |
| Permissions & Licensing | Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at: /site/misc/Permissions.xhtml |
| Reprints | Information about ordering reprints can be found online: /site/misc/reprints.xhtml |

PEDIATRICS is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. PEDIATRICS is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2010 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 0031-4005. Online ISSN: 1098-4275.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Increasing Prevalence of Medically Complex Children in US Hospitals

Katherine H. Burns, Patrick H. Casey, Robert E. Lyle, T. Mac Bird, Jill J. Fussell and
James M. Robbins

Pediatrics; originally published online September 20, 2010;
DOI: 10.1542/peds.2009-1658

The online version of this article, along with updated information and services, is
located on the World Wide Web at:
[/content/early/2010/09/20/peds.2009-1658](http://content.early/2010/09/20/peds.2009-1658)

PEDIATRICS is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. PEDIATRICS is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2010 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 0031-4005. Online ISSN: 1098-4275.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

