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Long-Term Health Care Utilization After Cardiac Surgery in Children Covered Under Medicaid

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ABSTRACT

BACKGROUND Understanding the longitudinal burden of health care expenditures and utilization after pediatric cardiac surgery is needed to counsel families, improve care, and reduce outcome inequities.

OBJECTIVES The purpose of this study was to describe and identify predictors of health care expenditures and utilization for Medicaid-insured pediatric cardiac surgical patients.

METHODS All Medicaid enrolled children age <18 years undergoing cardiac surgery in the New York State CHS-COLOUR database, from 2006 to 2019, were followed in Medicaid claims data through 2019. A matched cohort of children without cardiac surgical disease was identified as comparators. Expenditures and inpatient, primary care, subspecialist, and emergency department utilization were modeled using log-linear and Poisson regression models to assess associations between patient characteristics and outcomes.

RESULTS In 5,241 New York Medicaid-enrolled children, longitudinal health care expenditures and utilization for cardiac surgical patients exceeded noncardiac surgical comparators (cardiac surgical children: $15,500 ± $62,000 per month in year 1 and $1,600 ± $9,100 per month in year 5 vs noncardiac surgical children: $700 ± $6,600 per month in year 1 and $300 ± $2,200 per month in year 5). Children after cardiac surgery spent 52.9 days in hospitals and doctors' offices in the first postoperative year and 90.5 days over 5 years. Being Hispanic, compared with non-Hispanic White, was associated with having more emergency department visits, inpatient admissions, and subspecialist visits in years 2 to 5, but fewer primary care visits and greater 5-year mortality.

CONCLUSIONS Children after cardiac surgery have significant longitudinal health care needs, even among those with less severe cardiac disease. Health care utilization differed by race/ethnicity, although mechanisms driving disparities should be investigated further. (J Am Coll Cardiol 2023;81:1605–1617) © 2023 by the American College of Cardiology Foundation.

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ABBREVIATIONS AND ACRONYMS

NH = non-Hispanic

NYS = New York State

Nearly 1 million children and ~1.4 million adults live with congenital heart disease.[1] Since the first heart surgery in 1944, there have been tremendous improvements in operative mortality.[2,3] Nonetheless, the full burden of disease for the health care system and on patients and their families across the lifespan is incompletely understood.[4,5] Existing studies on health care utilization reflect only inpatient care or care received at single institutions. Further, most studies have relied on billed charges, which do not reflect actual dollars spent to provide care.[6,7] In addition, it is increasingly evident that substantial disparities in health outcomes, such as postoperative mortality, exist, even among children operated on at the same centers.[3,8,9] Examining the quantity and type of care being accessed over time by different groups of children will contribute to a deeper understanding of the underlying mechanisms behind these disparities, which is needed to identify effective measures to improve them.

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We sought to understand the long-term health care burden for publicly insured children after cardiac surgery and how these children utilize health care resources across time. We were particularly interested in the effects of disease severity and race and ethnicity. Using statewide, linked clinical registry and Medicaid data, we examined longitudinal Medicaid expenditures and the frequencies of inpatient, primary care, subspecialist, and emergency department visits, comparing children who did and did not undergo cardiac surgery. We then assessed risk factors for increased health care burden among pediatric cardiac surgical patients.

METHODS

DATA SOURCES. This was a retrospective analysis of prospectively collected data from the CHS-COLOUR (Congenital Heart Surgery Collaborative for Longitudinal Outcomes and Utilization of Resources) Registry. CHS-COLOUR links 14 years of locally held Society of Thoracic Surgeons-Congenital Heart Surgery Database and New York State Pediatric Congenital Cardiac Surgery clinical registry data from 10 of 11 pediatric cardiac surgical centers in New York State (NYS) to Centers for Medicare & Medicaid Services Medicaid claims on direct identifiers, 2006 through 2019.[10] NYS Centers for Medicare & Medicaid Services Medicaid data were also used to identify a noncardiac surgery comparison cohort.

Medicaid was listed as payor for 53% of NYS pediatric cardiac operations. Of these, 89% were linked to claims at operation. Detailed characteristics of this linkage have been previously reported in this journal.[10] In brief, children were matched via iterative deterministic matching, using first and last names; dates of birth; admit, discharge, or procedure dates; and family members' last names and alternate or prior last names, with fuzzy matching allowing for minor typos, alternate spellings, dates of birth with month and day flipped, or use of common name placeholders like "baby boy." On manual review, only 5 cases (<0.1%) were determined to be false positives. The linked cohort does not include children with cardiac defects who did not undergo surgical intervention.

POPULATION. We included all children age <18 years who underwent initial cardiac surgery while enrolled on NYS Medicaid for at least 1 postoperative month. Cardiac surgery was defined as all cardiopulmonary bypass and noncardiopulmonary bypass cardiovascular surgeries. We excluded children <2.5 kg who underwent surgical closure of isolated patent ductus arteriosus, in keeping with analytic standards for congenital heart research and public reporting.[11] A comparison cohort consisted of NYS Medicaid-enrolled children who did not undergo cardiac surgery, matched 1-to-1 from the overall Medicaid

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pediatric population on date of birth (± 6 months), age first Medicaid-enrolled (± 4 months), county of residence, sex, race/ethnicity, and duration of Medicaid enrollment. Because both children with cardiac disease and the broader pediatric population are at risk for other, noncardiac conditions (including prematurity), and because the presence of congenital heart disease increases the risk of many of these conditions, we did not match on noncardiac comorbidities. Therefore, the comparison cohort represents all other children on NYS Medicaid, not specifically healthy children.

OUTCOMES. We examined total health care expenditures and multidimensional measures of health care utilization. Total health care expenditures were defined as all payments made by NYS Medicaid, including to out-of-state providers, adjusted to 2019 dollars using the Medical Consumer Price Index.[12] Utilization measures included number and duration of inpatient admissions, number of emergency department visits, and outpatient primary care and subspecialty visits. Although not a primary endpoint, mortality was also assessed. Operative mortality was derived from the clinical registry and defined as death from any cause, occurring in-hospital or within 30 postoperative days if discharged before 30 days.[13] Long-term mortality was defined as death from any cause while Medicaid-enrolled.

OTHER DATA COLLECTED. Clinical characteristics were abstracted from the clinical registry.[14] Cardiac disease complexity was derived from fundamental diagnosis and grouped as: 1) critical single ventricle (single-ventricle physiology; requiring initial single-ventricle palliation within 60 days of life[15]; 2) critical biventricle (biventricular physiology, requiring operation within 60 days of life)[15]; 3) noncritical, infant repair (initial operation 60 days of life to 1 year); and 4) noncritical, childhood repair (initial operation after 1 year). Fundamental diagnosis was defined as the most complex cardiac anomaly or condition "carried with a patient through life, through all operations and hospitalizations."[16] Preoperative comorbidity was defined using standard Society of Thoracic Surgeons definitions, and included major noncardiac congenital anatomical abnormalities, chromosomal anomalies, or syndromes.[16] Due to imperfect reporting of race and ethnicity in both clinical and claims data, we utilized both data sources to assign race and ethnicity. Race and ethnicity were recorded at the time of enrollment on Medicaid in the claims data and were abstracted from electronic medical records in the clinical registry data. Race and ethnicity were categorized as Hispanic, non-Hispanic (NH) Asian, NH-Black, NH-White, or other. Other races included American Indian or Alaska Native, Native Hawaiian or Pacific Islander, or any other race. Data on children in the "other" category were not presented because of small sample size.

STATISTICAL ANALYSES. Demographics, clinical characteristics, expenditures, and health care utilization were summarized by cardiac disease complexity, year of initial operation, and duration of Medicaid enrollment after first cardiac surgery. Health care expenditures were calculated as mean or median dollars and utilization as encounters per person-month of Medicaid enrollment following initial cardiac surgery. Outcomes were compared with matched noncardiac Medicaid enrollees.

On the cardiac surgical population, multivariable regression was performed to evaluate predictors of health care expenditures and utilization. As we expected expenditures and utilization—and underlying mechanisms—to differ meaningfully between the first postoperative year and subsequent years, we assessed expenditures and utilization at 1 year and at 2 to 5 years after initial cardiac surgery. To assess associations between patient characteristics and health care expenditures and utilization, we adjusted all models for cardiac disease complexity, preoperative comorbidity, race/ethnicity, year of initial cardiac operation, sex, and surgical center. Covariates were chosen a priori based on being known risk factors for outcomes after cardiac surgery. We used log-linear models for health care expenditures and Poisson models that allowed for over dispersion for health care utilization. Models included an offset for time enrolled on Medicaid. In supplemental analyses, Cox proportional hazards models were used to assess predictors of mortality.

Additional analyses were undertaken to test the robustness of our results. First, some factors—such as family income and disability status—can affect health, health care utilization, and duration of Medicaid enrollment. To assess the effects of continuity of Medicaid enrollment, we repeated and compared analyses including noncontinuously Medicaid-enrolled children, while controlling for months enrolled as a covariate. Second, to assess potential effects of survivor bias, we repeated all analyses including and excluding patients who died during follow-up. As a more formal test of selection bias, Heckman selection models were also estimated for the 2- to 5-year multivariable models; Heckman models apply statistical correction to address bias introduced by nonrandomly selected samples—in this case, survival to 1 year.[17] Third, we recognized

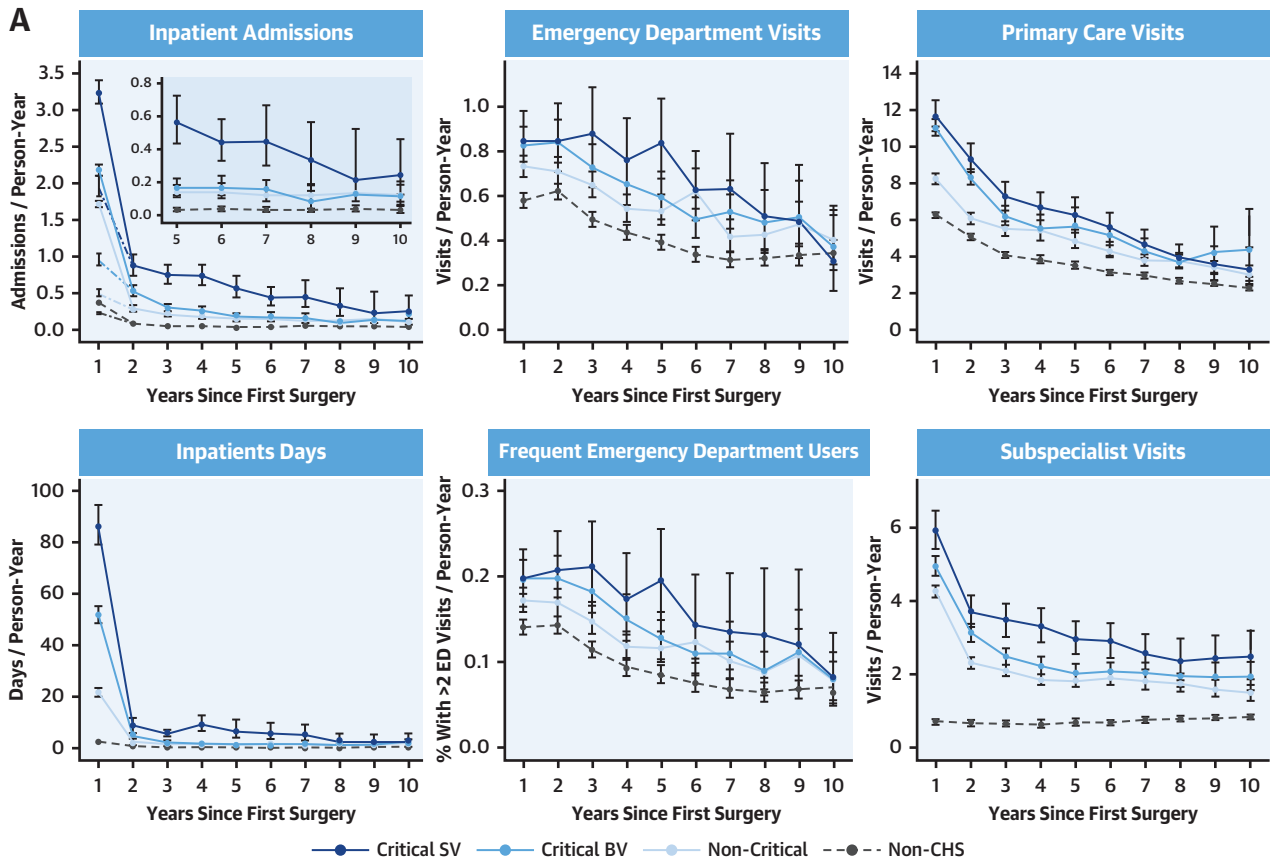
TABLE 1 Characteristics of New York Medicaid-Enrolled Children Undergoing Initial Cardiac Surgery

	All Children Medicaid-Enrolled at Cardiac Surgery Postoperative Year 1 (n = 5,247)	All Children Still Enrolled by Year 5 (n = 1,797)
Demographics and clinical characteristics[a]		
Cardiac disease complexity[b]		
Critical single ventricle, neonatal repair	666 (13)	201 (11)
Critical biventricle, neonatal repair	1,568 (30)	517 (30)
Noncritical, infant repair	1,622 (31)	536 (30)
Noncritical, childhood repair	1,385 (26)	543 (30)
Noncardiac congenital anomaly, chromosomal anomaly or syndrome	1,450 (28)	483 (27)
Race/ethnicity		
Hispanic	1,698 (32)	593 (33)
Non-Hispanic Asian	623 (12)	<236 (<13)
Non-Hispanic Black	1,178 (22)	400 (22)
Non-Hispanic White	1,701 (32)	580 (32)
Other/unknown	41 (1)	<12 (<1)
Age at operation, y	0.3 (0.0-1.5)	0.4 (0.0-2.3)
Female	2,438 (47)	802 (45)
Duration of initial hospitalization, d	9 (4-23)	8 (4-20)
Month of initial hospitalization	June 2013 (October 2009 to September 2016)	September 2010 (July 2008 to October 2012)
	First-Year Utilization for All Children Medicaid-Enrolled at Cardiac Surgery (n = 5,241) (56,098 person-mo)	**Fifth-Year Utilization for All Children Still Enrolled by Year 5 (n = 1,797) (21,490 person-mo)**
Unadjusted health care expenditures and utilization		
Cardiac surgical patients		
Medicaid expenditures, $/child/mo	$15,500 ± $62,000 ($700 [$100-$4,700])	$1,600 ± $9,100 ($100 [$0-$700])
Inpatient admissions, child/year, mo	0.17 ± 0.43 (0 [0-0])	0.02 ± 0.14 (0 [0-0])
Inpatient days, d admitted/child/mo	3.17 ± 17.67 (0 [0-0])	0.12 ± 2.83 (0 [0-0])
Emergency department, visits/child/mo	0.06 ± 0.29 (0 [0-0])	0.05 ± 0.25 (0 [0-0])
Primary Care, visits/child/mo	0.79 ± 1.19 (0 [0-1])	0.44 ± 0.96 (0 [0-1])
Subspecialist, visits/child/mo	0.39 ± 0.78 (0 [0-1])	0.17 ± 0.47 (0 [0-0])
Noncardiac surgical comparators[c]		
Medicaid expenditures, $/child/mo	$700 ± $6,600 ($0 [$0-$200])	$300 ± $2,200 ($0 [$0-$200])
Inpatient admissions, child/mo	0.03 ± 0.18 (0 [0-0])	0.00 ± 0.06 (0 [0-0])
Inpatient days, d admitted/child/mo	0.17 ± 2.66 (0 [0-0])	0.02 ± 0.61 (0 [0-0])
Emergency department, visits/child/mo	0.05 ± 0.24 (0 [0-0])	0.03 ± 0.20 (0 [0-0])
Primary care, visits/child/mo	0.52 ± 0.85 (0 [0-1])	0.29 ± 0.61 (0 [0-0])
Subspecialist, visits/child/mo	0.06 ± 0.28 (0 [0-0])	0.06 ± 0.30 (0 [0-0])

Values are n (%), median (IQR), or mean ± SD (median [IQR]). [a]Demographics and clinical characteristics are not presented for noncardiac surgical comparators because they were matched on these factors. [b]Cardiac disease complexity was derived from Society of Thoracic Surgeons-Congenital Heart Surgery Database fundamental diagnosis at time of first surgery, and grouped into the following categories: 1) critical single-ventricle physiology (single-ventricle physiology; requiring initial single ventricle palliation at ≤60 d of life); 2) critical biventricular physiology (biventricular physiology, but still requiring operation at ≤60 d of life); 3) noncritical congenital heart disease with initial operation in infancy (cardiac condition requiring surgery, with initial operation at 60 d to 1 y); and 4) noncritical congenital heart disease with initial operation in childhood (cardiac condition requiring surgery, with initial operation at >1 y of life). [c]Noncardiac surgical matched comparators were identified for 5,216 of 5,241 children Medicaid-enrolled and undergoing cardiac surgery in year 1 and 1,774 of 1,797 children Medicaid-enrolled and undergoing cardiac surgery in year 5.

that duration or intensity of initial hospitalization might affect 1-year health care expenditures and utilization. We were interested in understanding predictors of these outcomes both including and after initial hospital discharge. We therefore assessed health care expenditures and 1-year admission outcomes both including and excluding initial surgical/birth admission. Fourth, because prematurity was not routinely collected in older surgical registry data, models were tested with and without inclusion of prematurity for neonates and infants. Finally, because the frequency of well-child, primary care visits changes rapidly with age, the number of primary care visits in year 1 models was measured first in total and then recalculated to account for visits missed because of neonatal hospitalizations (Supplemental Table 1). Analyses were performed in Stata version 17.1 (StataCorp). Western Institutional Review Board approved this study with waiver of consent.

FIGURE 1 10-Year Health Care Utilization After Initial Cardiac Surgery



Stratified by **(A)** cardiac disease severity, **(B)** presence of preoperative comorbidities, and **(C)** race/ethnicity for all children regardless of duration of Medicaid enrolment. Note, the cohort changes across time because of year of initial operation and Medicaid disenrollment. BV = biventricle; CHS = congenital heart surgical children; NH = non-Hispanic; non-CHS = non-congenital heart surgical children; SV = single ventricle.

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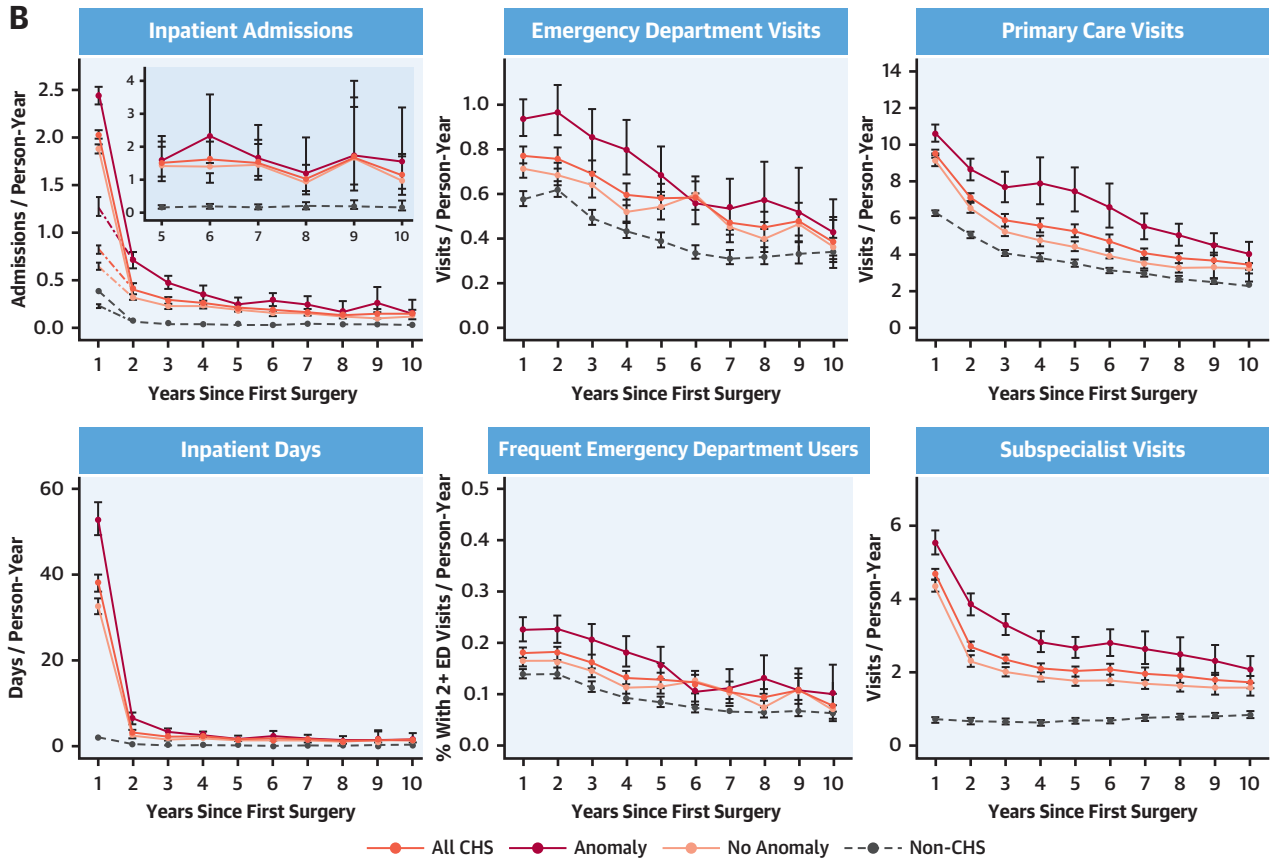
RESULTS

DEMOGRAPHICS, CLINICAL CHARACTERISTICS, AND MORTALITY. We identified 5,247 NYS Medicaid-enrolled children who underwent initial cardiac operation from 2006 to 2019, and 5,216 noncardiac surgical matched comparators (Supplemental Figure 1). Distributions of cardiac disease complexity, sex, races/ethnicities, and durations of initial hospitalizations were similar by duration of Medicaid enrollment. **Table 1** and Supplemental Table 2 present demographics and clinical characteristics by duration of Medicaid enrollment and year of initial repair. There was a slight decrease over time in the proportion of patients undergoing single ventricle repair (2006-2014 vs 2015-2018: 13.6% vs 10.7%) and an increase in the proportion with noncardiac congenital anomalies, chromosomal anomalies, or syndromes (2006-2014 vs 2015-2018: 24.8% vs 32.4%).

The 5-year survival after initial cardiac surgery was 90.9%, and median follow-up time until death, disenrollment from Medicaid, or end of study was 4.0 years (IQR: 1.3-5.0 years). The 5-year survival for matched noncardiac surgical comparators was >99.8%.

HEALTH CARE EXPENDITURES AND UTILIZATION. **Figure 1** displays 10-year health care utilization for cardiac vs noncardiac Medicaid enrollees, stratified by the following: 1) cardiac disease severity; 2) presence of preoperative comorbidities; and 3) race/ethnicity. **Table 1** compares 1- and 5-year unadjusted Medicaid expenditures and health care utilization.

FIGURE 1 Continued



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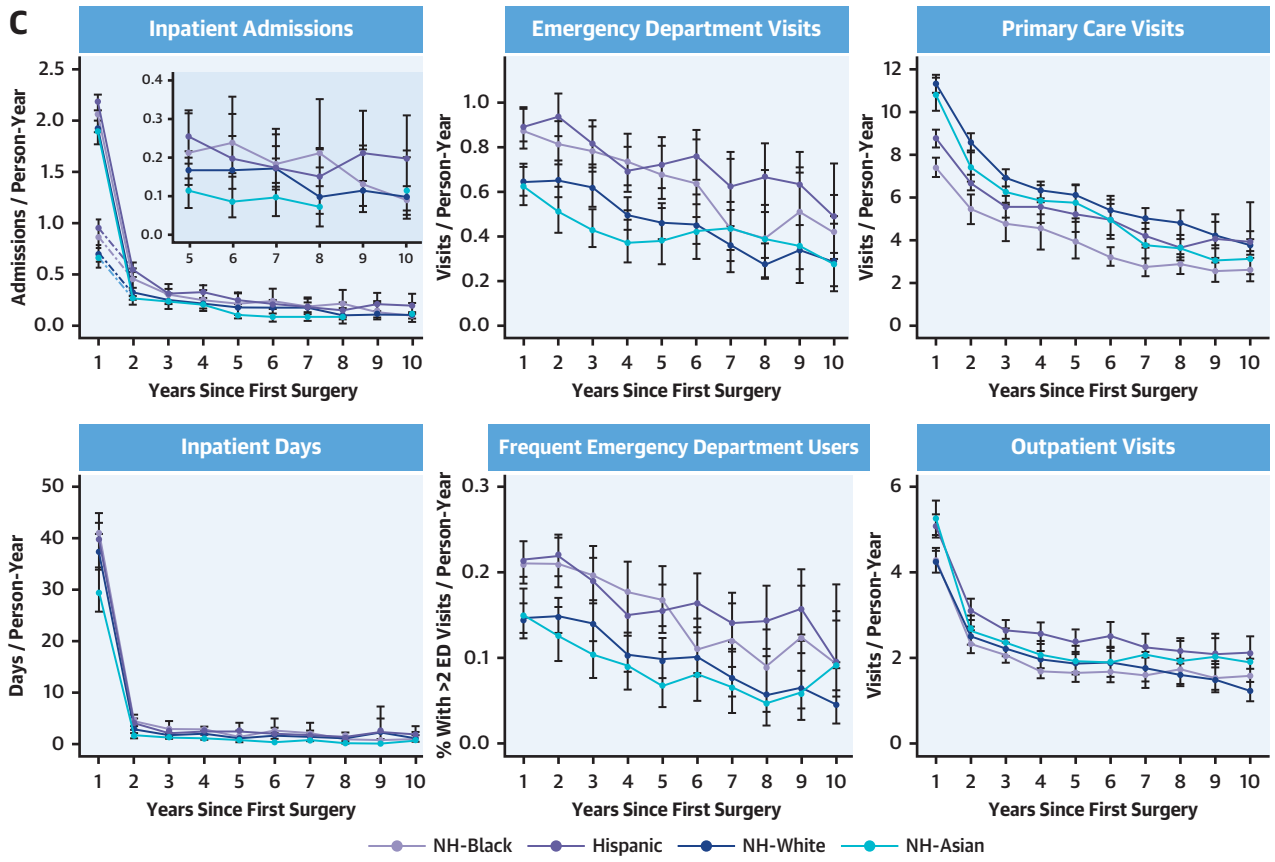
Overall mean Medicaid expenditures per child after cardiac surgery was $15,500 ± $62,000 per month in year 1 ($5,200 per month in year 1 after initial hospital discharge) and $1,600 ± $9,100 per month in year 5, reflecting an average of $186,000 expenditures and 52.9 days spent visiting doctors or in hospital in year 1, and $19,200 expenditures and 9.4 doctor/hospital days in year 5. In contrast, mean Medicaid expenditures for noncardiac surgical comparators was $700 ± $6,600 per month in the first year of matched enrollment ($500 excluding birth admissions) and $300 ± $2,200 per month in year 5, reflecting an average of $8,400 expenditures and 9.6 doctor/hospital days in year 1 and 4.8 doctor/hospital days in year 5.

Several additional patterns emerged from these data (Central Illustration, Figure 1). First, for cardiac surgical patients, the first postoperative year was particularly resource intensive across all care domains. Second, 5 years from operation, even children who underwent surgery for noncritical cardiac disease in infancy had 10% to 67% more primary care visits, 24% to 49% more emergency department visits, 137% to 185% more subspecialist visits, and 270% to 318% more inpatient admissions than children without cardiac surgical disease (Figure 1A). Third, even after initial hospitalization, health care expenditures were driven largely by inpatient admissions, with 87% of total cardiac patient expenditures year 1 (63% after initial hospitalization) and 35% year 5 attributable to inpatient stays (Central Illustration). This equated to an average of 38.0 hospital days per child in year 1 and 1.4 hospital days per child in years 2 to 5. In year 1, the majority of remaining expenditures were divided among chronic care (9%), pharmacy (8%), subspecialist and emergency department services (8%), early intervention/education services (4%), other (5%), and primary care (3%); by year 5, 30% of expenditures were attributable to chronic care services. Fourth, children undergoing higher-risk surgeries and those with comorbidities had higher utilization in year 1, but converged toward lower-risk children and children without comorbidities (Figures 1A and 1B). Finally,

FIGURE 1 Continued



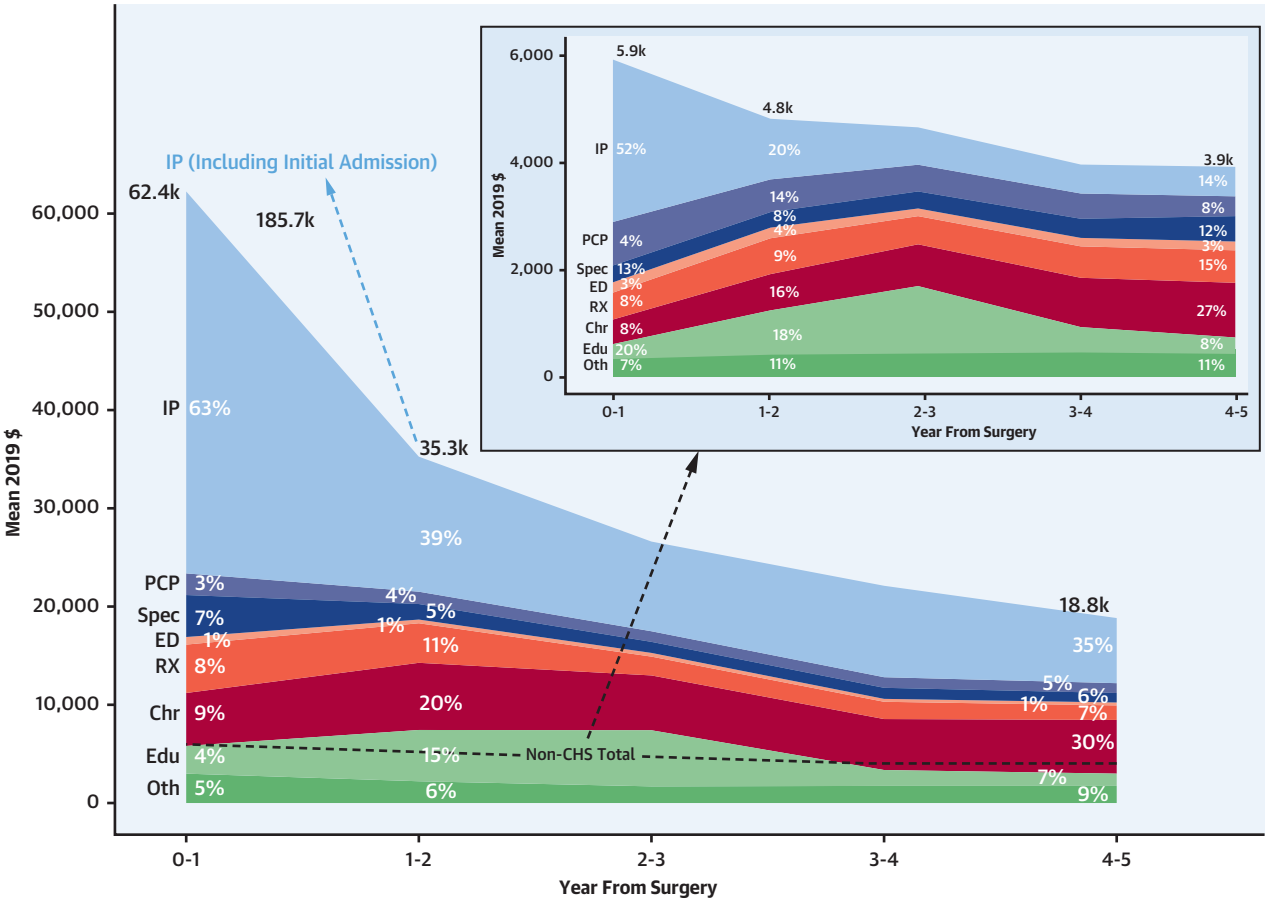
there was minimal difference in inpatient or emergency department utilization by year of initial operation, although there was evidence of increasing subspecialist visits from 2006 to 2019, and a suggestion of declining primary care visits after 2014 (**Figure 1D**). Supplemental Figure 2 presents detailed expenditures over time, stratified by race and ethnicity.

RISK FACTORS FOR HEALTH CARE UTILIZATION. **Figure 2, Table 2,** and Supplemental Table 3 present adjusted means and expenditure/incidence rate ratios for health care expenditures and utilization after cardiac surgery. Children with critical single-ventricle disease demonstrated the highest health care utilization, with average adjusted Medicaid expenditures of $233,000 per child in year 1 and $103,000 per child in years 2 to 5. In adjusted estimates, the average child with single-ventricle disease in the first postoperative year had 2.8 inpatient admissions (73.6 average inpatient days), and 0.8 emergency room, 10.8 primary care, and 5.7 subspecialist visits. In years 2 to 5, in adjusted estimates, the average child with single-ventricle disease had 2.1 inpatient admissions (20.1 average inpatient days) and 2.3 emergency room, 20.5 primary care, and 9.5 subspecialist visits.

The presence of preoperative comorbidities was associated with 54% (95% CI: 45%-64%) higher health care expenditures year 1, 29% (95% CI: 23%-34%) more inpatient admissions, and 15% to 26% (95% CI: 9%-41%) more emergency department, primary care, and subspecialist visits. Comorbidities were associated with 336% (95% CI: 270%-415%) higher expenditures in years 2 to 5, 99% (95% CI: 71%-132%) more admissions, and 30% to 57% (95% CI: 14%-72%) more health care visits (**Table 2**). Expenditures and utilization years 2 to 5 were largely insensitive to year of surgery, except for emergency department and subspecialist visits, which rose 3% (95% CI: 1%-5%) and 10% (95% CI: 8%-11%) per year. These associations were largely insensitive to changes in model assumptions or populations (**Figure 2**).

The 1-year adjusted health care expenditures were significantly higher for Hispanic and NH-Black than NH-White children (Hispanic vs NH-Black vs NH-

CENTRAL ILLUSTRATION **Longitudinal Health Care Expenditures for Children Enrolled in New York State Medicaid**



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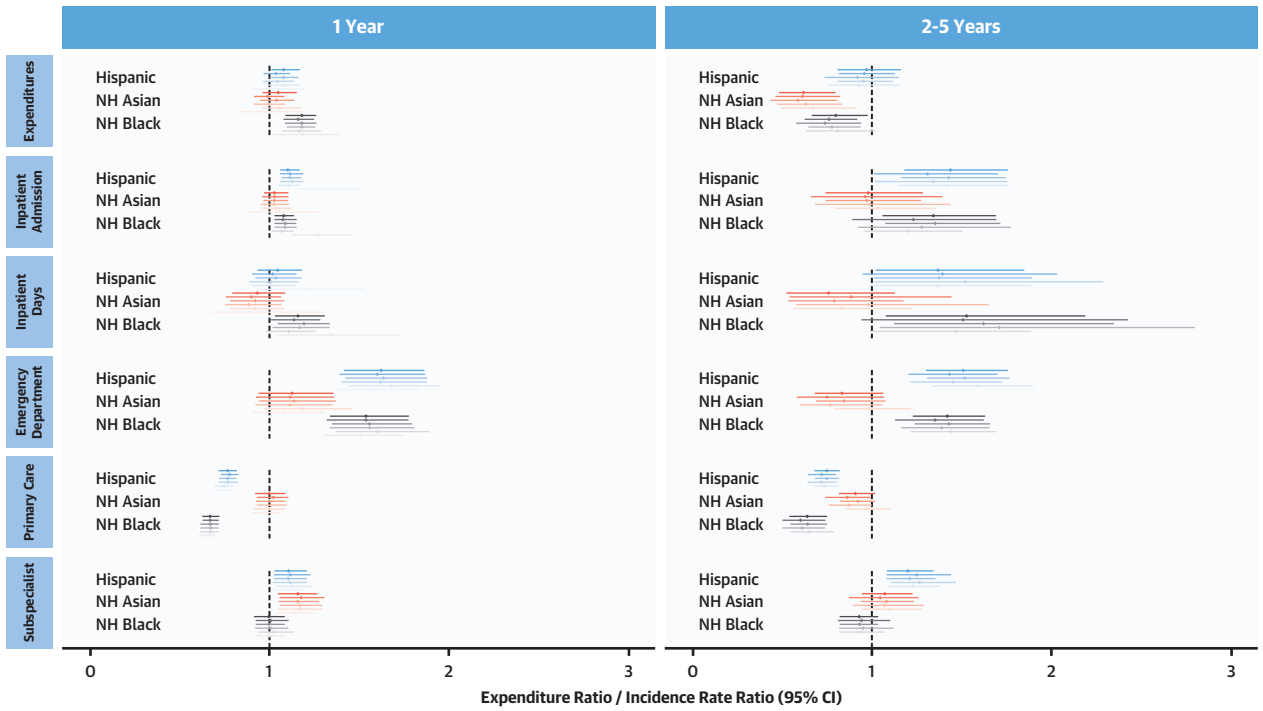
Expenditures are presented in U.S. 2019 dollars and represent mean dollars spent by New York State Medicaid from 2006 to 2019. The main figure represents children after initial cardiac surgery; the **inset** represents matched noncardiac comparators. For ease of interpretation, expenditures are grouped in the following categories: inpatient excluding initial hospitalization (IP); primary care practice (PCP); subspecialist (Spec); emergency department (ED); pharmacy (RX); rehabilitation/home health/and other chronic care services (Chr); early intervention/education (Edu); and other (Oth). Comparators **(black dashed lines)** were matched 1-to-1 from the overall Medicaid population on date of birth (±6 months), age first Medicaid-enrolled (±4 months), county of residence, gender, race/ethnicity, and duration of Medicaid enrolment. CHS = congenital heart surgical children; Non-CHS = non-congenital heart surgical children.

White: $116,687 vs $126,687 vs $107,623). The 2- to 5-year expenditures were lower for NH-Black and NH-Asian children compared with NH-White (NH-Black vs NH-Asian vs NH-White: $43,506 vs $34,952 vs $55,886); 2- to 5-year models were largely insensitive to mortality, disenrollment, duration of initial hospitalization, inclusion or exclusion of prematurity, and sample selection (Figure 2).

There were significant differences in health care utilization patterns across races and ethnicities. Compared with NH-White, Hispanic children, on average, experienced more inpatient admissions (11% [95% CI: 6%-17%] more year 1; 44% [95% CI: 18%-76%] more years 2-5), more emergency department visits (62% [95% CI: 41%-86%] more year 1; 51% [95% CI: 30%-76%] more years 2-5), and more subspecialist visits (11% [95% CI: 3%-21%] more year 1; 20% [95% CI: 8%-34%] more years 2-5), but saw primary care doctors less frequently (23% [95% CI: 27%-37%] less year 1; 25% [95% CI: 18%-32%] less years 2-5). NH-Black children experienced similar relative patterns of health care utilization, with more emergency department visits (54% [95% CI: 34%-78%] more year 1; 42% [95% CI: 23%-63%] more years 2-5) and fewer primary care visits (23% [95% CI: 18%-28%] fewer year 1; 36% [95% CI: 25%-46%] fewer years 2-5) than NH-White children. NH-Asian children experienced similar utilization to NH-White children year 1,

FIGURE 2 **Associations Between Race/Ethnicity and Longitudinal Health Care Expenditures and Utilization**



	Includes Mortalities	Includes Disenrollees	Includes Initial Hospitalization	Adjusted for Prematurity	N, 1-Year	N, 2-5 Years
Base Model	✓	✓	✓		5,241	3,940
2	✓		✓		4,479	1,843
3		✓	✓		4,905	3,894
4			✓		4,143	1,797
5	✓	✓	✓	✓	4,124	3,055
6	✓	✓			5,241	–

Among New York State Medicaid children undergoing initial cardiac surgery from 2006 to 2009, we used log-linear models for inflation-adjusted health care expenditures and Poisson models that allowed for over dispersion for count measures. Coefficients for expenditures were back transformed for ease of interpretation. All models were adjusted for sex, cardiac disease complexity, presence of preoperative comorbid condition, year of initial cardiac operation, and center. Patients with other race were included in models, but results were suppressed because of small sample size.

but had 16% (95% CI: 5%-27%) more subspecialist visits year 1. Results were largely insensitive to model choices (**Figure 2**, Supplemental Table 4, and Supplemental Figures 3 and 4).

Supplemental Table 5 presents adjusted HRs for operative and longitudinal mortality after cardiac surgery. Cardiac disease severity and presence of preoperative comorbidity were both strongly associated with operative and longitudinal mortality. In base models, NH-Black and Hispanic children had increased hazard for death over 5 years compared with NH-White children. Although with less statistical precision, similarly large effect sizes were observed across all sensitivity analyses and after excluding children who disenrolled. After excluding children who died in the immediate postoperative period, associations of race/ethnicity with longitudinal mortality were stronger.

DISCUSSION

This longitudinal, statewide study is the first to describe comprehensive, health care expenditures and utilization after pediatric cardiac surgery, as well as to analyze variation in the types and quantity of care used. Linking clinical registry data to longitudinal Medicaid claims enabled us to utilize clinical risk adjustment, while tracking care use over time and across institutions and health care domains. Medicaid-enrolled children had a significant health

TABLE 2 Risk Factors for Longitudinal Health Care Expenditures and Utilization

	Medicaid Expenditures		Inpatient Admissions		Inpatient Days Admitted	
	1-y	2-5 y[a]	1-y	2-5 y[a]	1-y	2-5 y[a]
	Spending Ratio (95% CI)		Incidence Rate Ratio (95% CI)			
Cardiac disease complexity[b] (reference group = noncritical, infant repair)						
Critical single ventricle,	2.67[c]	3.79[c]	1.68[c]	3.08[c]	3.06[c]	4.60[c]
neonatal repair	(2.45-2.91)	(2.92-4.92)	(1.59-1.79)	(2.57-3.71)	(2.67-3.51)	(3.43-6.17)
Critical biventricle, neonatal repair	1.70[c]	1.20	1.19[c]	1.43[c]	1.99[c]	1.61[c]
	(1.59-1.82)	(0.99-1.45)	(1.13-1.25)	(1.18-1.72)	(1.77-2.24)	(1.19-2.18)
Noncritical, childhood repair	0.68[c]	0.57[c]	0.82[c]	0.68[c]	0.52[c]	0.77
	(0.63-0.72)	(0.48-0.68)	(0.78-0.86)	(0.53-0.87)	(0.45-0.60)	(0.53-1.13)
Adjusted mean (reference group), $ or visits	$87,126	$27,190	1.7	0.7	24.0	4.4
Noncardiac congenital anomaly, chromosomal anomaly or syndrome (reference group = none)						
≥1	1.54[c]	4.36[c]	1.29[c]	1.99[c]	1.58[c]	2.17[c]
	(1.45-1.64)	(3.70-5.15)	(1.23-1.34)	(1.71-2.32)	(1.45-1.73)	(1.72-2.73)
Adjusted mean[d] (reference group), $ or visits	$100,867	$17,380	1.7	0.7	29.3	5.0
Race/ethnicity[e] (reference group = Non-Hispanic White)						
Hispanic	1.08[c]	0.97	1.11[c]	1.44[c]	1.05	1.37[c]
	(1.01-1.17)	(0.81-1.16)	(1.06-1.17)	(1.18-1.76)	(0.93-1.18)	(1.02-1.85)
Non-Hispanic Asian	1.05	0.62[c]	1.03	0.98	0.93	0.76
	(0.96-1.15)	(0.48-0.80)	(0.97-1.11)	(0.74-1.29)	(0.79-1.09)	(0.52-1.13)
Non-Hispanic Black	1.18[c]	0.80[c]	1.08[c]	1.34[c]	1.16[c]	1.53[c]
	(1.09-1.27)	(0.66-0.98)	(1.03-1.14)	(1.06-1.69)	(1.03-1.31)	(1.07-2.19)
Adjusted mean (reference group), $ or visits	$107,623	$36,727	1.7	0.7	32.5	5.3
Year of first cardiac operation	0.99	1.00	1.00	1.01	1.02[c]	1.00
	(0.99-1.00)	(0.98-1.03)	(0.99-1.00)	(0.99-1.03)	(1.00-1.03)	(0.97-1.04)

Assessed among New York Medicaid-Enrolled Children Undergoing Initial Cardiac Surgery from 2006-2019 (1-y: n = 5,241; 2-5 y: n = 3,940). We used log-linear models for inflation-adjusted health care expenditures and Poisson models that allowed for over dispersion for count measures. Ratios and means for expenditures were back transformed for ease of interpretation. Models also included sex and center fixed effects as control variables. [a]4-year sum over 2-5 y. [b]Cardiac disease complexity was derived from Society of Thoracic Surgeons-Congenital Heart Surgery Database fundamental diagnosis at time of first surgery, and grouped into the following categories: 1) critical single-ventricle physiology (single-ventricle physiology; requiring initial single-ventricle palliation at ≤60 d of life); 2) critical biventricle physiology (biventricular physiology, but still requiring operation at ≤60 d of life); 3) noncritical congenital heart disease with initial operation in infancy (cardiac condition requiring surgery, with initial operation at 60 d to 1 y); and 4) noncritical congenital heart disease with initial operation in childhood (cardiac condition requiring surgery, with initial operation at >1 y of life). [c]$P < 0.05$. [d]Geometric mean. [e]Patients with "other" race were included in the models, but results are suppressed because of small sample size.

Continued on the next page

care burden that persisted years after initial cardiac surgery. Hispanic and NH-Black children displayed different patterns of health care utilization than NH-White children, including fewer primary care and more emergency department visits.

Prior research on health care costs for children with cardiac conditions has relied on cost-to-charge ratio-based costs.[18] Although standardized cost-to-charge ratio-based costs facilitate important analyses on relative resource utilization, they are not synonymous either with the dollars paid or with the underlying value of billed goods or service. Indeed, only a fraction of health care spending is charge based, and charges for individually billed items vary widely.[6,19] Our study is the first to describe dollars spent for health care-related services for pediatric cardiac surgical patients. Further, most prior studies captured only inpatient resources and did not capture the breadth of health care use for patients over time.[20-22] Our study, in contrast, captures total Medicaid expenditures—for inpatient, outpatient, emergency room, rehabilitation, home health and other chronic care services, pharmacy, early intervention/education, and so on—both across institutions and across time and then further elucidates the number and types of health care encounters, providing insight into the longitudinal total burden of disease.

On average, Medicaid-enrolled children undergoing cardiac surgery had expenditures of $139,000 per child over the first 5 postoperative years ($263,000 including initial hospitalization), compared with $20,000 per child for children without cardiac surgery ($23,000 including birth hospitalizations). Readmissions represented a high burden for both payors and patients long after initial cardiac operation; >50% of expenditures in the first postoperative year and one-third of expenditures years 2 through 5 were attributable to admissions. Home health and other chronic care services, although used by a minority of

TABLE 2 Continued

Emergency Department Visits		Primary Care Visits		Subspecialist Visits	
1-y	2-5 y[a]	1-y	2-5 y[a]	1-y	2-5 y[a]
Incidence Rate Ratio (95% CI)					
1.10	1.15	1.20[c]	1.15[c]	1.47[c]	1.63[c]
(0.85-1.43)	(0.95-1.39)	(1.11-1.29)	(1.02-1.30)	(1.33-1.61)	(1.45-1.85)
1.10	1.00	1.09[c]	1.02	1.16[c]	1.22[c]
(0.93-1.30)	(0.87-1.14)	(1.03-1.15)	(0.92-1.14)	(1.08-1.24)	(1.10-1.36)
0.69[c]	0.66[c]	0.59[c]	0.69[c]	0.89[c]	0.88[c]
(0.60-0.80)	(0.58-0.77)	(0.54-0.64)	(0.61-0.77)	(0.82-0.97)	(0.78-0.98)
0.8	2.0	9.0	17.8	3.9	5.8
1.26[c]	1.30[c]	1.15[c]	1.42[c]	1.24[c]	1.57[c]
(1.13-1.41)	(1.14-1.47)	(1.09-1.21)	(1.28-1.57)	(1.16-1.33)	(1.44-1.72)
0.6	1.7	8.1	14.9	3.9	5.5
1.62[c]	1.51[c]	0.77[c]	0.75[c]	1.11[c]	1.20[c]
(1.41-1.86)	(1.30-1.76)	(0.63-0.72)	(0.68-0.82)	(1.03-1.21)	(1.08-1.34)
1.13	0.83	1.00	0.91	1.16[c]	1.07
(0.94-1.36)	(0.68-1.01)	(0.92-1.09)	(0.82-1.02)	(1.05-1.27)	(0.94-1.23)
1.54[c]	1.42[c]	0.77[c]	0.64[c]	1.00	0.93
(1.34-1.78)	(1.23-1.63)	(0.72-0.82)	(0.54-0.75)	(0.91-1.09)	(0.82-1.04)
0.5	1.5	10.0	20.1	3.9	6.0
1.01	1.03[c]	0.98[c]	1.00	1.07[c]	1.10[c]
(1.00-1.03)	(1.01-1.05)	(0.98-0.99)	(0.99-1.01)	(1.07-1.08)	(1.08-1.11)

patients, also contributed substantially to expenditures, accounting for 20% to 30% of expenditures, and might represent another important area for quality-of-life improvement and cost containment. Emergency room visits represented only 1% of NYS Medicaid expenditures. Similarly, early intervention/education services—for a population known to be at risk of developmental delay and learning challenges—represented only 1% of expenditures.

The average family on NYS Medicaid with a child with cardiac surgical disease spent 46.8 days in hospitals and doctors' offices in the first postoperative year and 90.5 days over 5 years. This equates to approximately 3 months of potential lost days of parental work and child educational opportunities per household and more than 4 months (143 days) per household for families with children with single-ventricle disease. Further, the number of subspecialist appointments per patient per year more than doubled over 12 years and health care utilization persisted well above noncardiac comparators even 10 years after initial surgery. Understanding the magnitude of this burden might facilitate conversations between patients and providers regarding care coordination and streamlining of any unnecessary care.

Our study also identified significant differences in the ways in which families of pediatric cardiac surgical patients accessed care. Previous studies have described disparities in mortality, length-of-stay, and acute care resource utilization by race and ethnicity.[3,23-26] We reaffirmed previous observations of disparate mortality and expanded upon this, showing that NH-Black and Hispanic children were seen less often in primary care offices and more often in emergency rooms. In some models, NH-Black and Hispanic children also had more subspecialist visits and spent more days in hospital than NH-White children. The reasons for the variation in patterns of care according to race and ethnicity are unclear, especially because most Medicaid-enrolled children have low-income families. These differences were associated with increased Medicaid expenditures for NH-Black and Hispanic children in the first year and decreased expenditures for NH-Black children (and NH-Asian) in years 2 to 5. Further investigations are needed to understand the causal mechanisms behind differences in care utilization according to race and ethnicity. One needs to understand, eg, whether they result from greater postoperative morbidity among NH-Black and Hispanic children—

pointing to issues during or before the operative stay—or whether they reflect diverse access to postoperative providers.

STUDY LIMITATIONS. First, in longitudinal claims data, patients enter and leave cohorts at different times, making claims analyses susceptible to sample selection bias. We performed multiple sensitivity analyses to assess potential bias, and our results were largely insensitive to differences in enrollment duration or death, although we cannot rule out the possibility that sample selection influenced our findings.

Second, our results might not be generalizable to privately insured patients or outside of NYS. That said, >50% of pediatric cardiac surgical patients are covered by Medicaid, and publicly insured children have worse outcomes after cardiac surgery than privately insured patients, making them a critical population to understand and for whom to improve care.[8,10] Future work would ideally expand to include private payor data and other geographic regions.

Third, although the linkage of Medicaid claims to clinical registry data allowed us to employ robust preoperative clinical risk adjustment, it is possible that patients differed in other meaningful ways not captured in the surgical registries. Both race/ethnicity data sources are self-reported, and although there is evidence to suggest improving fidelity within New York administrative data, the accuracy of race/ethnicity data from administrative and registry sources must always be questioned.[27] Some races did not have large enough sample sizes to analyze individually and so were grouped under "unknown/other." Additionally, although children of "unknown" race/ethnicity died disproportionately during their initial admission, these data were missing for <1% of patients. Children of multiple races were not reliably coded in either the registries or Medicaid, and therefore were not analyzed.

Fourth, presenting diagnoses or indications for clinical care are of variable accuracy in administrative data. Therefore, we characterized the quantity of health care visits, but not the indications for these visits. We also did not differentiate between subspecialist visits to pediatric cardiologists vs other subspecialist providers.

Finally, although we captured total expenditures paid by Medicaid, our data did not include out-of-pocket expenses, lost wages, or other costs associated with care. In interpreting our data, these additional expenses should also be considered.

CONCLUSIONS

We provide the first comprehensive description of longitudinal health care expenditures and utilization in children after cardiac surgery. Care for these children does not end after surgery. There are also marked differences in types of care used by race/ethnicity across time. Understanding the burden children and families experience after surgery might allow clinicians to better counsel their patients, families to prepare for the future, and providers and parents to advocate for more resources for post-surgery care. Further investigations into differences in utilization can help delineate underlying mechanisms behind, and ways to improve, longitudinal outcome disparities.

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PERSPECTIVES

COMPETENCY IN PATIENT CARE AND PROCEDURAL SKILLS: Even children with less severe cardiac disease have substantially greater health care utilization 5 years after surgery than those who do not undergo heart surgery.

TRANSLATIONAL OUTLOOK: More research is needed to overcome disparities in utilization of health care services after pediatric heart surgery based on race and ethnicity.

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KEY WORDS children, expenditures, health care utilization, longitudinal, Medicaid

APPENDIX For supplemental tables and figures, please see the online version of this paper.