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ORIGINAL RESEARCH

Health Care Usage Among Adolescents With Congenital Heart Defects at 5 Sites in the United States, 2011 to 2013

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BACKGROUND: We sought to characterize health care usage for adolescents with congenital heart defects (CHDs) using population-based multisite surveillance data.

METHODS AND RESULTS: Adolescents aged 11 to 18 years with ≥1 CHD-related diagnosis code and residing in 5 US sites were identified in clinical and administrative data sources for the years 2011 to 2013. Sites linked data on all inpatient, emergency department (ED), and outpatient visits. Multivariable log-binomial regression models including age, sex, unweighted Charlson comorbidity index, CHD severity, cardiology visits, and insurance status, were used to identify associations with inpatient, ED, and outpatient visits. Of 9626 eligible adolescents, 26.4% (n=2543) had severe CHDs and 21.4% had Charlson comorbidity index >0. At least 1 inpatient, ED, or outpatient visit was reported for 21%, 25%, and 96% of cases, respectively. Cardiology visits, cardiac imaging, cardiac procedures, and vascular procedures were reported for 38%, 73%, 10%, and 5% of cases, respectively. Inpatient, ED, and outpatient visits were consistently higher for adolescents with severe CHDs compared with nonsevere CHDs. Adolescents with severe and nonsevere CHDs had higher health care usage compared with the 2011 to 2013 general adolescent US population. Adolescents with severe CHDs versus nonsevere CHDs were twice as likely to have at least 1 inpatient visit when Charlson comorbidity index was low (Charlson comorbidity index =0). Adolescents with CHDs and public insurance, compared with private insurance, were more likely to have inpatient (adjusted prevalence ratio, 1.5 [95% CI, 1.3–1.7]) and ED (adjusted prevalence ratio, 1.6 [95% CI, 1.4–1.7]) visits.

CONCLUSIONS: High resource usage by adolescents with CHDs indicates a substantial burden of disease, especially with public insurance, severe CHDs, and more comorbidities.

Key Words: adolescent ■ heart defects, congenital ■ inpatients ■ outpatients ■ prevalence

Congenital heart defects (CHDs) are the most common birth defects, occurring in 1 in 100 newborns.[1] Survival has improved, enabling the majority of individuals to live with CHD as a chronic condition. Individuals with CHD continue to have a lifelong risk of cardiovascular complications and may require further surgical or catheter-based therapies, leading to increased health care usage.[1] Additionally, noncardiac surgery and pregnancy often require specialists who are familiar with CHDs. Resource usage is higher in adolescents and adults with CHD compared with individuals without CHDs.[2–4] There are often multiple gaps in care

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CLINICAL PERSPECTIVE

What Is New?

- Adolescents with congenital heart defects (CHDs) have higher health care usage as compared with the general US adolescent population.
- Severe CHDs, public insurance, and comorbidities were risk factors that led to high health care usage.
- Adolescents with CHDs who had at least 1 encounter with a cardiologist were less likely to have an emergency department visit.

What Are the Clinical Implications?

- Individuals with CHDs have a lifelong risk of cardiovascular complications and may require further surgical or catheter-based therapies, leading to increased health care usage.
- Adolescents with CHDs should be made aware of the importance of lifelong congenital cardiac care. Reducing barriers to continuous cardiac care may reduce emergency department encounters.

Nonstandard Abbreviations and Acronyms

CCI	Charlson comorbidity index
CHD	congenital heart defect

as adolescent patients with CHDs transition from pediatric to adult care. As a result, >50% of patients[5] are lost to cardiac follow-up, which may contribute to adverse outcomes over their life span.[6] In one study, the number of hospital admissions via the emergency department (ED) was shown to have nearly doubled during the age of transition in patients with CHDs.[7]

Pediatric hospitalizations for patients with CHDs account for 15% of all pediatric hospitalization costs in the United States.[8] Critical CHDs account for 17% of cases but for 27% of all CHD hospitalization costs.[8] Infants account for a disproportionate amount of costs.[9] Few studies have examined health care usage into childhood and adolescence. Lu et al[2] demonstrated that CHD health care encounters were fewer during adolescence compared with adulthood. However, the number of unplanned admissions for arrhythmia and heart failure steadily increased from adolescence into adulthood and was more pronounced in those who were uninsured or with public health insurance. This suggests potential gaps in access to care for adolescents with CHDs.

As the population of children and adolescents living with CHDs grows and ages, the costs to hospitals for care of individuals hospitalized for CHDs can be expected to increase. Investigating factors associated with ED visits and hospitalization for adolescents with CHDs will help plan for the future needs of this growing population. The goal of this analysis is to estimate health care usage in adolescents who had a CHD-coded health care encounter through linkage of population-based surveillance data at 5 US sites.

METHODS

Because of the sensitive nature of the data collected for this study, requests to access the data set from qualified researchers trained in human subject confidentiality protocols may be sent to the Centers for Disease Control and Prevention at jill.glidewell@cdc.hhs.gov.

Case Definition and Severity Classification

Cases were identified using *International Classification of Diseases, Ninth Revision, Clinical Modification* (*ICD-9-CM*) diagnostic codes 745.xx to 747.xx, excluding congenital heart block (746.86), absent/hypoplastic umbilical artery (747.5), pulmonary arteriovenous malformation (747.32), other anomalies of peripheral vascular system (747.6x), and other specified anomalies of circulatory system (747.8x). The CHD diagnostic codes were classified into mutually exclusive hierarchical groups similar to Marelli et al,[10,11] integrating both hemodynamic severity and basic anatomy: severe, shunt (excludes isolated 745.5), shunt+valve, valve, other CHD, and isolated secundum atrial septal defects versus patent foramen ovale (defined as 745.5 alone or with 746.89 or 746.9). Although 745.5 is the code used for secundum atrial septal defect, isolated 745.5 was excluded from this analysis because of its use for the normal variant patent foramen ovale.[12] Cases that fell into the "other CHD" category were also excluded because of poor positive predictive value for CHD in preliminary validation studies. Shunt, shunt+valve, and valve CHDs were further grouped into nonsevere CHD. Severe CHDs included endocardial cushion defects, interrupted aortic arch, tetralogy of Fallot, total anomalous pulmonary venous return, transposition complexes, truncus, and univentricular hearts. Cases with only 1 code were classified as either severe CHD or nonsevere CHD. Cases with multiple codes were classified as severe if they had at least 1 severe CHD code, regardless of the presence of other CHD codes.

Case Ascertainment

Using administrative and clinical data sources, we identified adolescents between the ages of 11 and 18 years who had a health care encounter with an eligible CHD diagnosis code between January 1, 2011, and December

31, 2013, and who had a residential address in 1 of the 5 site-specific catchment areas at some point in the 3-year surveillance period.[13] The University of Colorado–Denver identified cases statewide using the Colorado Congenital Heart Disease Surveillance System, which includes electronic health records and health insurance claims data from 5 primary case-finding data sources in Colorado.[14] Emory University in Atlanta, Georgia identified cases in 5 metropolitan Atlanta area counties (Clayton, Cobb, Dekalb, Fulton, and Gwinnett) in Georgia using administrative and clinical data from 6 pediatric and adult care facilities and from Georgia state Medicaid data. The New York State Department of Health identified cases in 11 counties (Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Monroe, Niagara, Orleans, and Wyoming in the west and Bronx and Westchester in the south) based on administrative data from 7 pediatric cardiology clinics, Medicaid claims data, and hospital inpatient and outpatient data from the New York Statewide Planning and Research Cooperative System. Duke University in Durham, North Carolina, identified cases statewide using electronic health records in 5 pediatric and adult care facilities in North Carolina. The University of Utah identified cases statewide using the Utah Population Database, which links multiple data sources, including the Utah Birth Defect Network, a statewide population-based birth defect surveillance system, and electronic health records in the 2 major health care systems in Utah.

Demographic Characteristics

Descriptive variables included age at first encounter with a CHD diagnosis code in the 2011 to 2013 surveillance period (ie, first qualifying health care encounter), sex, race (White, Black, other [which includes individuals classified as Asian, American Indian/Alaska Native, Native Hawaiian/Pacific Islander, or Multiracial]), ethnicity (Hispanic, non-Hispanic), and insurance status. Insurance status for the 3-year period was categorized on the basis of a hierarchy: (1) If any encounter for the individual listed Medicaid or Medicare, the insurance status was classified as “any public”; (2) if any encounter listed private, other government, or other insurance, insurance status was classified as “private (no public)”; (3) if all encounters indicated self-pay or no insurance, insurance status was classified as “none”; otherwise, (4) insurance status was classified as “unknown.”

Comorbidity, Health Care Usage, and Procedure Classification

The unweighted Charlson comorbidity index (CCI) was used to assess non-CHD burden of disease and has been used to predict mortality and higher resource usage in administrative data and other pediatric populations.[4,15] The CCI was assessed using the *ICD-9-CM* diagnostic codes of medical comorbidties in patients with CHDs during any health care encounter.[16] The unweighted CCI includes myocardial, vascular, pulmonary, gastrointestinal, renal, hepatic, neurologic, oncologic, and immune conditions.[15]

Health care usage was assessed from health care encounters including those with and without CHD codes in adolescents with CHD. These health care encounters were categorized as visits (inpatient, ED, or outpatient) and specific cardiac procedure categories (cardiac imaging, cardiac procedure, or vascular procedure). Multiple visits on the same day were counted as one visit, and the visit was coded using the following hierarchy: (1) inpatient, (2) ED, and (3) outpatient. An outpatient cardiology visit was defined as an outpatient encounter with a cardiology provider type (see Table S1 for definition); provider-type data was available for Colorado, Georgia, New York, and Utah.

Cardiac procedures were derived from *ICD-9-CM* and Current Procedural Terminology codes in the cardiac- and vascular-related procedural Clinical Classification Software tool. Clinical Classification Software is a categorization scheme, developed by the Agency for Healthcare Research and Quality, which collapses thousands of *ICD-9-CM* and Current Procedural Terminology codes into >200 diagnostic and procedure categories.[17] *ICD-9-CM* codes other than CHD diagnoses and all Current Procedural Terminology codes across all CHD-related visits were first grouped into categories of comorbidities and procedures using the Clinical Classification Software tool with some modifications, that is, removal of symptoms. The *ICD-9-CM* and CPT codes in the cardiac- and vascular-related procedural Clinical Classification Software categories were further collapsed into the following project-specific cardiac procedure categories: cardiac imaging, cardiac procedures, and vascular procedures (Table S2). Procedural codes that do not fall into 1 of these 3 categories (eg, knee replacement) were considered noncardiac procedures and are not described in this analysis.

Statistical Analysis

Deidentified, deduplicated demographic, encounter, and summary data, which combined and reconciled information from multiple data sources, were transmitted by all 5 sites to the Centers for Disease Control and Prevention via a secure mechanism. Descriptive statistical analyses evaluated differences in the distribution of demographics and health care usage for CHD cases by CHD severity and surveillance site. Summary statistics were calculated for health care visits/procedures per case and inpatient length of stay. Chi-square tests (2-sided tests, alpha=0.05) were used to assess whether there were significant differences in the

proportion of cases with at least 1 visit/procedure by CHD severity and surveillance site.

Rates of inpatient and ED visits among adolescents with CHD were compared with the rates among all US adolescents using population-level data from the Centers for Disease Control and Prevention Wonder, discharge data from the National Inpatient Sample, and discharge data from the Nationwide Emergency Department Sample Healthcare Cost and Utilization Project, Agency for Healthcare Research and Quality.[18,19] Population denominator data for each site were estimated by averaging 2011, 2012, and 2013 US Census estimates as described in Glidewell et al[13] To assess factors associated with the probability of at least 1 inpatient and ED visit and at least 1 cardiac imaging, cardiac procedure, and vascular procedure, we constructed multiple log-binomial regression models to generate adjusted prevalence ratios with corresponding 95% CIs. Both race and ethnicity were excluded from the models because of the substantial percentage of unknown values. We used multiple imputation (n=20 imputations) by fully conditional specification to impute missing values for insurance status, which had <10% unknown values, and sex, which had 1 missing value.[20,21] Age at first qualifying encounter, sex, CHD severity, insurance status, and CCI were included in final models. Presence of at least 1 outpatient cardiology visit during the surveillance period was included as an additional predictor in the inpatient and ED models. For the multivariable models, we used the likelihood ratio test (alpha=0.05) to assess for interaction between CCI by sex, insurance type, and CHD severity, as well as between insurance type by CHD severity; ultimately, the only interaction term included was CCI by CHD severity as indicated. North Carolina visits were excluded from the inpatient and ED models with cardiology visit because provider type was missing for all cases. Because the provider type variable was unknown for at least 1 outpatient visit among 33% to 71% of cases at the other 4 sites, we also conducted sensitivity analyses on the impact of this variable for the inpatient and ED visit models by excluding 4077 cases who did not report any outpatient cardiology visits but reported at least 1 outpatient visit with an unknown provider type (Table S1).

All analyses were performed with SAS software version 9.3 (SAS Institute, Inc, Cary, NC). Compilation and sharing of deidentified data with the Centers for Disease Control and Prevention were approved by each participating site's institutional review board.

RESULTS

There were 9626 adolescents with a documented CHD diagnosis code identified from the 5 sites (Table 1). Of those, 2543 (26%) adolescents had severe CHDs. The median age category was 14 to 16 years; 57% were male; 54% were White, 15% Black, 5% other, and for 26% race was missing; 15% were Hispanic, 59% non-Hispanic, and 27% unknown Hispanic ethnicity. Race varied across sites with 49% White, 4% Black, 14% other in Colorado; 38% White, 29% Black, 4% other in Georgia; 50% White, 20% Black, 6% other in New York; 64% White, 21% Black, 2% other in North Carolina; 66% White in Utah (Black and other were too small to report in Utah). Ethnicity also varied by site with highest proportions of Hispanic adolescents in Colorado (24%) and New York (31%). Insurance coverage at the 5 sites included 50% private, 43% any public, 1% self-pay/uninsured, and 6% unknown. Patients with severe CHDs more often had public insurance compared with nonsevere CHDs (49% versus 40%, $P<0.0001$). More than 1 in 5 adolescents with CHDs (21.4%) had CCI >0.

At least 1 inpatient, ED, and outpatient visit was reported for 21%, 25%, and 96% of identified adolescents with CHDs, respectively (Table 2). Colorado, New York, and Utah had higher ED visits (24%, 53%, and 26%, respectively) as compared with inpatient visits (11%, 22%, and 17%, respectively). A higher proportion of the adolescents with severe CHDs had inpatient and ED visits compared with nonsevere CHDs (inpatient visit: 29% versus 18%, $P<0.0001$; ED visit: 28% versus 24%, $P<0.0001$). Of adolescents with CHDs, 38% had a documented outpatient cardiology visit (Colorado, Georgia, New York, Utah), and 73% had a cardiac imaging exam between 2011 and 2013. Prevalence varied by site; Atlanta, Georgia, had the highest percentage of adolescents with ≥1 documented outpatient cardiology visits (78%), while Utah had the lowest (16%). A larger percentage of adolescents with severe CHDs had ≥1 documented outpatient cardiology visits (41%) or at least 1 outpatient cardiology visit and cardiac imaging exam (81%) compared with those with nonsevere CHDs (37% and 73%, respectively) ($P<0.001$ for both) (Table 2). The proportion of adolescents with severe CHDs with at least 1 documented outpatient cardiology visit remained relatively consistent for each of the 3 surveillance years (25%, 28%, and 28% in 2011, 2012, and 2013, respectively), treating all severe cases identified over the surveillance period as the denominator (data not shown). Fifty-four percent, 41%, and 37% of individuals with at least 1 outpatient visit related to cardiac imaging, cardiac procedures, or vascular procedures, respectively, were reported as having seen a cardiology provider for the visit (Table S3).

Cardiac imaging (73%) was the most common type of procedure for adolescents with CHDs compared with other cardiac (10%) and vascular (5%) procedures (Table 2). A higher percentage of adolescents with severe CHD had cardiac imaging, cardiac procedures, and vascular procedures compared with nonsevere

Table 1. Demographics of Adolescents With a Documented CHD-Related *ICD-9-CM* Code in at Least 1 Health Care Encounter, 5 Sites, 2011–2013

Variable	All sites, n (%)			Colorado, n (%)			Georgia, n (%)			New York, n (%)			North Carolina, n (%)			Utah, n (%)		
	Overall	Severe CHD	Nonsevere CHD	Overall	Severe CHD	Nonsevere CHD	Overall	Severe CHD	Nonsevere CHD	Overall	Severe CHD	Nonsevere CHD	Overall	Severe CHD	Nonsevere CHD	Overall	Severe CHD	Nonsevere CHD
Total	9626 (100)	2543 (26.4)	7083 (73.6)	2023 (21.0)	522 (25.8)	1501 (74.2)	1559 (16.2)	456 (29.25)	1103 (70.8)	1830 (19.0)	474 (25.9)	1356 (74.1)	2475 (25.7)	643 (26.0)	1832 (74.0)	1739 (18.1)	448 (25.8)	1291 (74.2)
Age at first qualifying encounter																		
11–13 y	4235 (44.0)	1155 (45.4)	3080 (43.5)	1026 (50.7)	274 (53.0)	752 (50.1)	637 (40.9)	195 (42.8)	442 (40.1)	701 (38.3)	175 (36.9)	526 (38.8)	1031 (41.7)	271 (42.2)	760 (41.5)	840 (48.3)	240 (53.6)	600 (46.5)
14–16 y	3524 (36.6)	906 (35.6)	2618 (37.0)	659 (32.6)	155 (29.7)	504 (33.6)	604 (38.7)	183 (40.1)	421 (38.2)	715 (39.1)	193 (40.7)	522 (38.5)	963 (38.9)	239 (37.2)	724 (39.5)	583 (33.5)	136 (30.4)	447 (34.6)
17–18 y	1867 (19.4)	482 (19.0)	1385 (14.4)	338 (16.7)	93 (17.8)	245 (16.3)	318 (20.4)	78 (17.1)	240 (21.8)	414 (22.6)	106 (22.4)	308 (22.7)	481 (19.4)	133 (20.7)	348 (19.0)	316 (18.2)	72 (16.1)	244 (18.9)
Sex																		
Male	5436 (56.5)	1410 (55.4)	4026 (56.8)	1171 (57.9)	286 (54.8)	885 (59.0)	853 (54.7)	234 (51.3)	619 (56.1)	995 (54.4)	266 (56.1)	729 (53.8)	1414 (57.1)	370 (57.5)	1044 (57.0)	1003 (57.7)	254 (56.7)	749 (58.0)
Female	4189 (43.5)	1133 (44.6)	3056 (43.1)	851 (42.1)	236 (45.2)	615 (41.0)	706 (45.3)	222 (48.7)	484 (43.9)	835 (45.6)	208 (43.9)	627 (46.2)	1061 (42.9)	273 (42.5)	788 (43.0)	736 (42.3)	194 (43.3)	542 (42.0)
Missing	1 (0)	0 (0)	1 (0)	1 (0)	0 (0)	1 (0.1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Race																		
White	5220 (54.2)	1420 (55.8)	3800 (53.6)	988 (48.8)	259 (49.6)	729 (48.6)	587 (37.7)	174 (38.2)	413 (37.4)	916 (50.1)	233 (49.2)	683 (50.4)	1577 (63.7)	422 (65.6)	1155 (63.1)	1152 (66.2)	332 (74.1)	820 (63.5)
Black	1432 (14.9)	445 (17.5)	987 (13.9)	79 (3.9)	26 (5.0)	53 (3.5)	459 (29.4)	168 (36.8)	291 (26.4)	367 (20.1)	99 (20.9)	268 (19.8)	513 (20.7)	147 (22.9)	366 (20.0)	*	*	*
Other[†]	514 (5.3)	148 (5.8)	366 (5.2)	282 (13.9)	84 (16.1)	198 (13.2)	68 (4.4)	28 (6.1)	40 (3.6)	102 (5.6)	24 (5.1)	78 (5.8)	60 (2.42)	12 (1.9)	48 (2.6)	*	*	*
Unknown	2460 (25.6)	530 (20.8)	1930 (27.2)	674 (33.3)	153 (29.3)	521 (34.7)	445 (28.5)	86 (18.9)	359 (32.6)	445 (24.3)	118 (24.9)	327 (24.1)	325 (13.1)	62 (9.6)	263 (14.4)	571 (32.8)	111 (24.8)	460 (35.6)
Ethnicity																		
Hispanic	1445 (15.0)	390 (15.3)	1055 (14.9)	494 (24.4)	139 (26.6)	355 (23.7)	93 (6.0)	30 (6.58)	63 (5.7)	561 (30.7)	157 (33.1)	404 (29.8)	155 (6.3)	35 (5.4)	120 (6.6)	142 (8.17)	29 (6.5)	113 (8.75)
Non-Hispanic	5631 (58.5)	1644 (64.6)	3987 (56.3)	1213 (60.0)	315 (60.3)	898 (59.8)	1041 (66.8)	348 (76.3)	693 (62.8)	1188 (64.9)	310 (65.4)	878 (64.8)	1679 (67.8)	466 (72.5)	1213 (66.2)	510 (29.3)	205 (45.8)	305 (23.6)
Unknown	2550 (26.5)	509 (20.0)	2041 (28.8)	316 (15.6)	68 (13.0)	248 (16.5)	425 (27.3)	78 (17.1)	347 (31.5)	81 (4.4)	7 (1.5)	74 (5.5)	641 (25.9)	142 (22.1)	499 (27.2)	1087 (62.5)	214 (47.8)	873 (67.6)
Insurance status																		
Any public	4113 (42.7)	1249 (49.1)	2864 (40.4)	959 (47.4)	285 (54.6)	674 (44.9)	729 (46.8)	254 (55.7)	475 (43.1)	1142 (62.4)	327 (69.0)	815 (60.1)	816 (33.0)	237 (36.9)	579 (31.6)	467 (26.85)	146 (32.6)	321 (24.9)
Private (no public)	4803 (49.9)	1174 (46.2)	3629 (37.7)	1022 (50.5)	228 (43.7)	794 (52.9)	821 (52.7)	199 (43.6)	622 (56.4)	676 (36.9)	142 (30.6)	531 (39.2)	1026 (41.5)	304 (47.3)	722 (39.4)	1258 (72.3)	298 (66.5)	960 (74.4)

(*Continued*)

Table 1. (Continued)

Variable	All sites, n (%)			Colorado, n (%)			Georgia, n (%)			New York, n (%)			North Carolina, n (%)			Utah, n (%)		
	Overall	Severe CHD	Nonsevere CHD	Overall	Severe CHD	Nonsevere CHD	Overall	Severe CHD	Nonsevere CHD	Overall	Severe CHD	Nonsevere CHD	Overall	Severe CHD	Nonsevere CHD	Overall	Severe CHD	Nonsevere CHD
None	92 (1.0)	17 (0.2)	75 (0.8)	39 (1.9)	9 (1.7)	30 (2.0)	8 (0.5)	3 (0.7)	5 (0.5)	12 (0.7)	2 (0.4)	10 (0.7)	30 (1.2)	2 (0.3)	28 (1.5)	*	*	*
Unknown	618 (6.4)	103 (4.1)	515 (7.3)	3 (0.15)	0 (0)	3 (0.2)	1 (0.1)	0 (0)	1 (0.09)	0 (0)	0 (0)	0 (0)	603 (24.4)	100 (15.6)	503 (27.5)	*	*	*
Charlson comorbidity index																		
0	7565 (78.6)	1864 (73.3)	5701 (80.5)	1639 (81.0)	389 (74.5)	1250 (83.3)	1303 (83.6)	353 (77.4)	950 (86.1)	1327 (72.5)	318 (67.1)	1009 (74.4)	2021 (81.7)	509 (79.2)	1512 (82.5)	1275 (73.3)	295 (65.9)	980 (75.9)
1	1602 (16.6)	483 (19.0)	1119 (15.8)	308 (15.2)	98 (18.8)	210 (14.0)	186 (11.9)	63 (13.8)	123 (11.2)	385 (21.0)	113 (23.8)	272 (20.1)	345 (13.9)	94 (14.6)	251 (13.7)	378 (21.7)	115 (25.7)	263 (20.4)
2	323 (3.4)	134 (5.3)	189 (2.6)	55 (2.7)	24 (4.6)	31 (2.07)	46 (2.95)	29 (6.4)	17 (1.5)	78 (4.3)	24 (5.1)	54 (4.0)	78 (3.2)	29 (4.5)	49 (2.7)	66 (3.8)	28 (6.3)	38 (2.9)
3+	136 (1.4)	62 (2.4)	74 (1.0)	21 (1.0)	11 (2.1)	10 (0.67)	24 (1.5)	11 (2.4)	13 (1.2)	40 (2.2)	19 (4.0)	21 (1.6)	31 (1.3)	11 (1.7)	20 (1.1)	20 (1.15)	10 (2.2)	10 (0.8)

CHD indicates congenital heart defect; and *ICD-9-CM*, *International Classification of Diseases, Ninth Revision, Clinical Modification*.
* Suppressed due to small cell size.
†"Other" race category contains individuals classified as Asian, American Indian/Alaska Native, Native Hawaiian/Pacific Islander, or Multiracial.

CHDs (cardiac imaging, 80% versus 71%; cardiac procedure, 20% versus 6%; vascular procedure, 11% versus 3%; *P*<0.0001 for all).

Rates of inpatient and ED visits were consistently higher for adolescents with severe (892 inpatient visits and 703 ED visits per 1000 people) compared with nonsevere CHDs (551 inpatient visits and 643 ED visits per 1000 people), and both had higher health care usage compared with the general adolescent US population in 2011 to 2013 (25 inpatient visits and 301 ED visits per 1000 people) (Figure 1). In both the multivariable analyses among 7135 complete cases with known sex and insurance status and 7151 cases after multiple imputation, age, female sex, and public insurance were associated with having at least 1 inpatient visit, whereas age, public insurance, and increasing CCI were associated with having at least 1 ED visit (Table 3). Severe CHD was associated with having at least 1 inpatient visit only for those with low CCI (CCI=0). Adolescents with ≥1 documented outpatient cardiology visits were less likely to experience an ED visit in the surveillance period (Figure 2). The most frequent type of non-CHD diagnoses among inpatient and ED visits were cardiac and pulmonary including cardiac dysrhythmias and respiratory failure (Table S4).

Increasing CCI was associated with higher ED and inpatient visits (Figure 3). In unadjusted analysis, CHD severity and increasing CCI were associated with having at least 1 cardiac imaging procedure, at least 1 cardiac procedure, and at least 1 vascular procedure, respectively (Table 4). Additionally, compared with private insurance, those with public insurance were less likely to have at least 1 cardiac imaging procedure but more likely to have at least 1 cardiac procedure or at least 1 vascular procedure. In adjusted analysis, adolescents with public insurance (adjusted prevalence ratio, 0.9 [95% CI, 0.8–0.9]) were still less likely to have at least 1 cardiac imaging procedure, but associations between insurance and cardiac and vascular procedures were attenuated. Severe CHD was most strongly associated with receiving cardiac imaging, and cardiac and vascular procedures for those with lower CCI scores. Associations with CHD severity were attenuated at CCI scores of 3 and 4, depending on outcome.

DISCUSSION

In population-based surveillance of CHD in 5 US sites, most of the health care encounters for adolescents aged 11 to 18 years were outpatient visits. There was variation in health care usage at the 5 sites with larger percentages of adolescents with ED use, compared with inpatient visits, in Colorado, New York, and Utah. A higher proportion of the adolescents with severe CHD

Table 2. Visits and Procedures for Adolescents With a Documented CHD-Related *ICD-9-CM* Code in at Least 1 Health Care Encounter, by Site and CHD Severity, 2011–2013

	Overall	Severe CHD	Nonsevere CHD	*P* value	Colorado	Georgia	New York	North Carolina	Utah	*P* value
Total cases	9626	2543	7083		2023	1559	1830	2475	1739	
Inpatient visits										
Cases with at least 1 inpatient visit	2028 (21.1)	724 (28.5)	1293 (18.3)	<0.0001	225 (11.1)	220 (14.1)	410 (22.4)	872 (35.2)	301 (17.3)	<0.0001
No. of unique inpatient visits, median*	2	2	2		1	1	1	2	2	
Emergency department visits										
Cases with at least 1 visit in emergency department	2404 (25.0)	708 (27.8)	1696 (23.9)	<0.0001	475 (23.5)	119 (7.6)	970 (53.0)	385 (15.6)	455 (26.2)	<0.0001
No. of emergency department visits per person, median*	2	1	2		2	1	2	2	1	
Outpatient (clinic and nonemergency department) visits										
Cases with at least 1 outpatient visit	9208 (95.7)	2461 (96.8)	6747 (95.3)	0.0013	1972 (97.5)	1533 (98.3)	1795 (98.1)	2172 (87.8)	1736 (99.8)	<0.0001
No. of outpatient visits*	4	6	4		3	3	6	4	6	
Outpatient cardiologist visits, median†										
Cases with at least 1 outpatient cardiologist visit	3644 (37.9)	1039 (40.9)	2605 (36.8)	0.0003	1342 (66.3)	1215 (77.9)	817 (44.6)		270 (15.5)	
Number of outpatient cardiologist visits, median*	2	3	1		2	2	1		1	
Cardiac imaging‡										
Cases with at least 1 procedure	7066 (73.4)	2025 (79.6)	5041 (71.2)	<0.0001	1295 (64.0)	1472 (94.4)	1608 (87.9)	1083 (43.8)	1608 (92.5)	<0.0001
No. of procedures, median	6	10	5		5	5	10	4	7	
Cardiac procedures/surgeries‡										
Cases with at least 1 procedure	922 (9.6)	500 (19.7)	422 (6.0)	<0.0001	70 (3.5)	141 (9.0)	196 (10.7)	309 (12.5)	206 (11.9)	<0.0001
No. of procedures, median	4	4	4		1	4	5	3	5	
Vascular procedures‡										
Cases with at least 1 procedure	518 (5.4)	283 (11.1)	235 (3.3)	<0.0001	23 (1.1)	61 (3.9)	114 (6.2)	188 (7.6)	132 (7.6)	<0.0001
No. of procedures, median	2	3	2		2	2	3	2	2	

CHD indicates congenital heart defect; and *ICD-9-CM, International Classification of Diseases, Ninth Revision, Clinical Modification.*

*Median number among cases with at least 1 visit or procedure recorded.

†Outpatient cardiology visits excludes North Carolina site.

‡Type of cardiac imaging, cardiac procedures/surgeries, and vascular procedures are shown in Table S2.

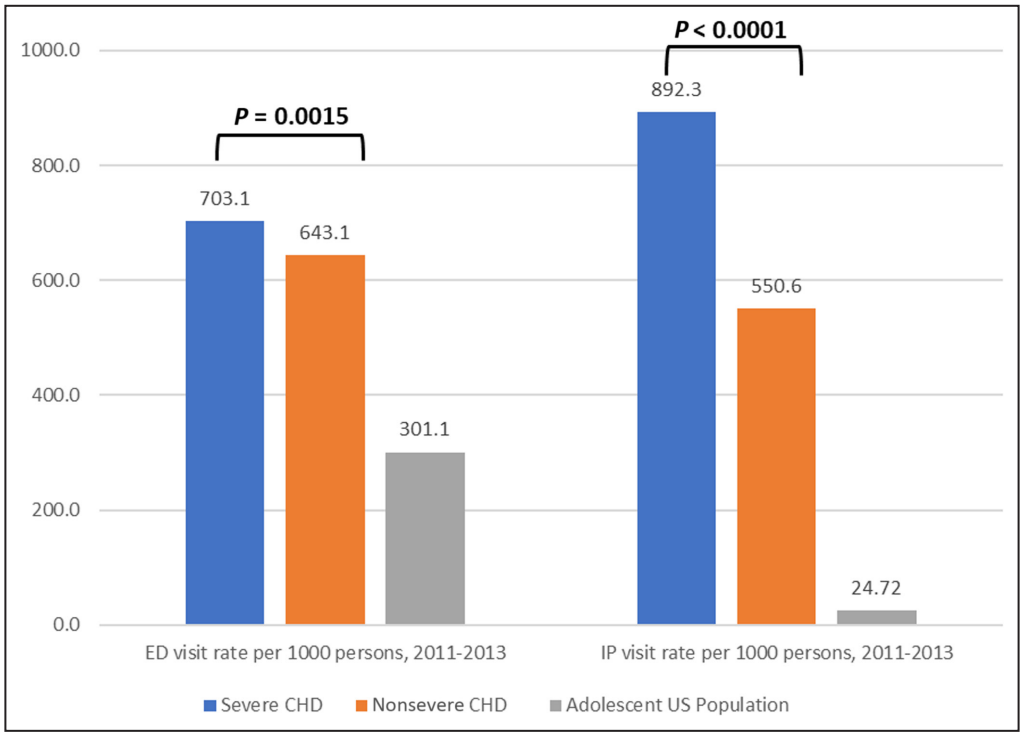

Figure 1. Inpatient and ED visit rate for adolescents with a documented CHD-related *International Classification of Diseases, Ninth Revision, Clinical Modification* (*ICD-9-CM*) code in at least 1 health care encounter, by severity, compared with the general US adolescent population, over the 2011 to 2013 surveillance period.

Inpatient and emergency department visit data for the US adolescent population was obtained from the National Inpatient Sample, the Nationwide Inpatient Sample, and the Nationwide Emergency Department Sample, Healthcare Cost and Utilization Project. CHD indicates congenital heart defect; ED, emergency department; and IP, inpatient.

had inpatient and ED visits compared with nonsevere CHD. Public insurance was associated with both inpatient and ED visits, while increased CCI was associated with ED visits. Larger percentages of adolescents with public insurance had cardiac and vascular procedures, but fewer had cardiac imaging. Adolescents with severe CHD and increasing CCI were more likely to have cardiac and vascular procedures and cardiac imaging. Additionally, patients with a documented outpatient cardiology visit during the surveillance period had a lower likelihood of an ED visit. Outpatient cardiology visits in adolescents with CHD is an encouraging and important health care usage for continuity of care in this patient population and may provide an avenue for reducing ED health care usage.

Prior studies have examined health care usage in adolescents and young adults with CHDs. Compared with other age groups, infants with CHDs have the most ED visits, which then progressively decrease with age.[22] However, the number of ED visits rises again in late adolescence, with a 40% increase in young adulthood.[7] Lu et al[2] demonstrated that the percentage of ED admissions also increases as adolescents with CHDs transition to adult care, and that increase is more pronounced in the uninsured and those with public insurance. Similarly, public insurance was associated with increased prevalence of inpatient and ED visits for this cohort. While inpatient and ED visits were more common among adolescents with CHDs with public insurance, cardiac imaging was less common among this group, compared with adolescents with private insurance. Because limited access to care remains common in adolescents with CHDs,[2] patients with public insurance may seek care for cardiac symptoms at the ED that could have been assessed and managed during an outpatient cardiology visit.[2,7,22] Previous research has also identified public insurance as a predictor of adverse pediatric cardiac surgical outcomes compared with commercial or managed care pediatric patients.[23–25] In this cohort of adolescents with CHDs, 1% were uninsured, likely representing the availability of public insurance and adolescent coverage under parental insurance. However, as adolescents with CHDs transition to adulthood, individuals with CHDs aged 19 to 39 years have the lowest percentage of insurance coverage of any age

Table 3. Predictors of ≥1 Inpatient Visits and Emergency Department Visits Among Adolescents With Documented CHD-Related *ICD-9-CM* Code in at Least 1 Health Care Encounter, 5 Sites, 2011–2013

	At least 1 inpatient visit						At least 1 ED visit					
	Bivariate		Multivariable: complete case*,†		Multivariable: multiple imputation*,‡		Bivariate		Multivariable: complete case*,†		Multivariable: multiple imputation*,‡	
	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value
Age, y, at first qualifying encounter‡	1.03 (1.00–1.06)	0.0225	1.03 (1.00–1.05)	0.0294	1.03 (1.00–1.05)	0.0316	1.02 (1.00–1.04)	0.0306	1.02 (1.00–1.04)	0.0156	1.02 (1.00–1.04)	0.0180
Sex‖												
Male (ref)												
Female	1.18 (1.05–1.32)	0.0061	1.14 (1.02–1.28)	0.0223	1.14 (1.02–1.28)	0.0229	1.10 (1.01–1.20)	0.0323	1.08 (0.99–1.18)	0.0989	1.08 (0.99–1.18)	0.0953
Insurance status¶												
Any public	2.10 (1.86–2.37)	<0.0001	1.47 (1.29–1.67)	<0.0001	1.47 (1.29–1.67)	<0.0001	1.83 (1.68–2.01)	<0.0001	1.57 (1.43–1.72)	<0.0001	1.57 (1.43–1.73)	<0.0001
Private (no public; ref)												
None	1.05 (0.50–2.22)	0.8975	1.13 (0.54–2.39)	0.7473	1.13 (0.54–2.40)	0.7404	0.79 (0.42–1.47)	0.4568	0.84 (0.45–1.57)	0.5894	0.84 (0.45–1.57)	0.5931
CHD severity‡												
Nonsevere (ref)												
Severe	1.81 (1.61–2.03)	<0.0001					1.12 (1.02–1.24)	0.0191	1.00 (0.91–1.10)	0.9728	1.00 (0.91–1.10)	0.9867
Charlson comorbidity index‡												
0 (ref)												
1	3.47 (3.04–3.95)	<0.0001					2.00 (1.81–2.21)	<0.0001	1.81 (1.63–2.00)	<0.0001	1.81 (1.64–2.00)	<0.0001
2	6.60 (5.51–7.92)	<0.0001					2.67 (2.25–3.17)	<0.0001	2.31 (1.94–2.75)	<0.0001	2.31 (1.94–2.75)	<0.0001
3+	9.04 (7.21–11.33)	<0.0001					3.11 (2.46–3.94)	<0.0001	2.53 (1.99–3.22)	<0.0001	2.54 (2.00–3.22)	<0.0001
Charlson comorbidity index by CHD severity												
Severe vs nonsevere at Charlson score=0 (ref)			2.07 (1.74–2.47)	<0.0001	2.08 (1.74–2.48)	<0.0001						
Severe vs nonsevere at Charlson score=1			1.15 (0.93–1.41)	0.1898	1.14 (0.93–1.40)	0.2000						
Severe vs nonsevere at Charlson score=2			1.10 (0.79–1.51)	0.5795	1.09 (0.79–1.51)	0.5815						
Severe vs nonsevere at Charlson score=3+			0.82 (0.54–1.25)	0.3556	0.82 (0.54–1.25)	0.3541						

(*Continued*)

Table 3. (Continued)

	At least 1 inpatient visit						At least 1 ED visit					
	Bivariate		Multivariable: complete case*,†		Multivariable: multiple imputation*,‡		Bivariate		Multivariable: complete case*,†		Multivariable: multiple imputation*,‡	
	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value
Outpatient cardiologist visit#,‡												
No (ref)												
Yes	0.90 (0.80–1.01)	0.0770	1.01 (0.90–1.14)	0.8189	1.02 (0.90–1.14)	0.7785	0.78 (0.71–0.85)	<0.0001	0.86 (0.79–0.94)	0.0011	0.86 (0.79–0.95)	0.0014

CHD indicates congenital heart defect; and *ICD-9-CM, International Classification of Diseases, Ninth Revision, Clinical Modification*.
*Model adjusted for all variables listed in the table; model includes an interaction between Charlson score and CHD severity.
†Case count for specified model was n=7135.
‡Case count for specified model was n=7151.
§Prevalence ratio.
‖Case count for specified model was n=7150.
¶Case count for specified model was n=7136.
#Cases identified at North Carolina site were excluded from models because information on outpatient cardiology visits was unavailable.

group, highlighting the vulnerability of this population who need lifelong care.[26] Additionally, rates of employment and high school education are lower in individuals with CHDs as compared with the general population.[27] This may have an impact on insurance coverage for adults with CHDs since coverage is primarily based on employer-sponsored health insurance in the United States. This study supports our prior pilot surveillance finding that CHD severity is a risk factor for higher health care usage among US adolescents with CHDs and highlights that those with public insurance may have higher health care usage as well.[28] Health care usage such as hospitalization has been shown to be higher in patients with CHDs as compared with the general population.[29] Models of disease burden in individuals with CHDs have demonstrated increased medical spending, with decrements in life expectancy, employment, and lifetime earnings.[27,30] Understanding risk factors for increased health care usage is necessary to reduce the overall burden of disease.

Prior studies examining the number of cardiology visits in adolescents and adults with CHDs show that having fewer outpatient visits with a cardiologist is associated with a higher risk of loss of follow-up cardiology care during childhood.[5,31] During a 5-year period, 45% of adolescents aged 13 to 17 years with CHDs in Quebec were seen by a cardiologist.[31] In our cohort, a slightly lower percentage of adolescents had ≥1 documented outpatient cardiology visits over a 3-year period (38%); however, 42% of remaining cases had at least 1 outpatient visit with missing/unknown provider type. Not having a documented outpatient cardiology visit was associated with having an ED visit. More information is needed on whether outpatient cardiology visits for adolescents with CHDs prevent cardiac emergencies and, subsequently, reduce ED admissions, or whether this association is related to access to health care. ED admissions comprise a large proportion of health care usage in the CHD population.[2,22] Therefore, the frequency of cardiology follow-up for adolescents with CHDs remains an important part of their care and may reduce ED visits. A consensus statement by Wernovsky et al[32] suggested that children with severe CHDs, such as transposition of the great arteries, tetralogy of Fallot, and single ventricle, should receive outpatient cardiology care at least annually. We were unable to examine loss to follow-up in our cohort because of the 3-year surveillance period, but the proportion of severe cases with at least 1 reported outpatient cardiology visit remained relatively consistent for each of the 3 surveillance years. The percentage of adolescents having ≥1 documented outpatient cardiology visits varied by site from 78% of adolescents in Atlanta, Georgia, to only 16% in Utah. This variation may be secondary to sites' data sources or lack of data on provider type. Additionally, 73% of

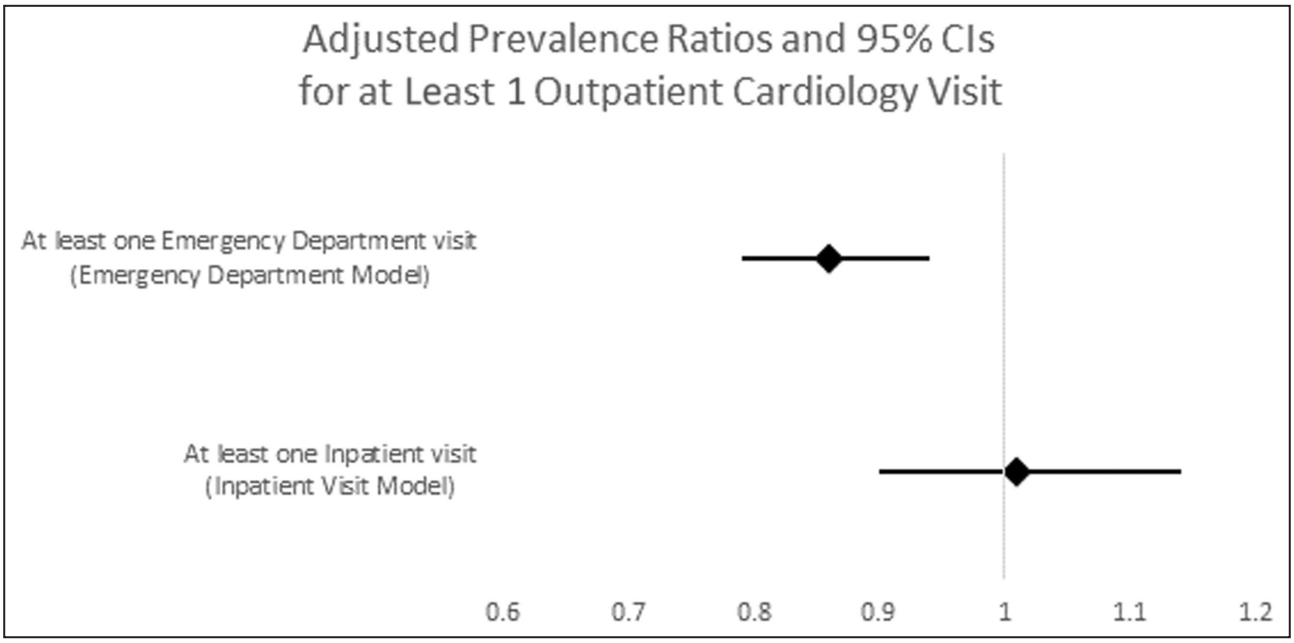

Figure 2. Associations between an outpatient cardiology visit and at least 1 emergency department visit and inpatient visit, respectively, in multivariable complete-case analysis.
CHD indicates congenital heart defect; and ED, emergency department.

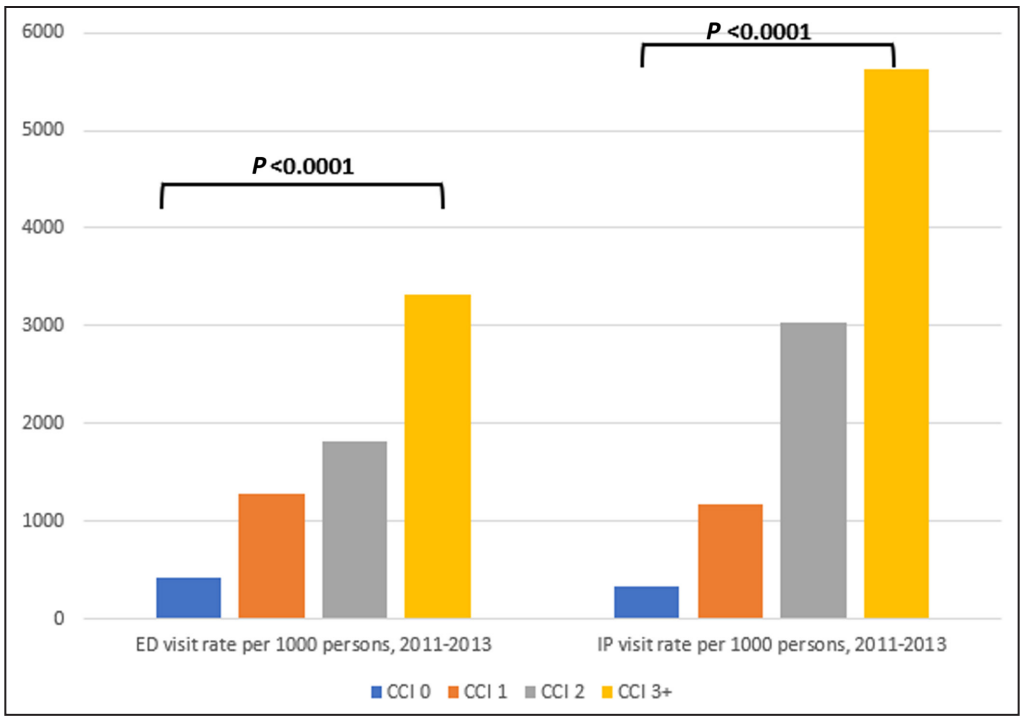

Figure 3. Inpatient and ED visit rate for adolescents with a documented CHD-related *International Classification of Diseases, Ninth Revision, Clinical Modification* (*ICD-9-CM*) code in at least 1 health care encounter, by unweighted Charlson Comorbidity Index score, compared with the general US adolescent population, over the 2011 to 2013 surveillance period.
CHD indicates congenital heart defect; ED, emergency department; and IP, inpatient.

adolescents had at least 1 cardiac imaging procedure, which suggests a potentially higher percentage with some touch point with a cardiologist, although only 47% of these cardiac imaging procedures were associated with a cardiology provider (Table S3). Some of these imaging studies may have been done in a

Table 4. Predictors of at Least 1 Cardiac Imaging Procedure, Cardiac Procedure, or Vascular Procedure Among Adolescents With a Documented CHD-Related *ICD-9-CM* Code in At Least 1 Health Care Encounter, 5 Sites, 2011–2013

	At least 1 cardiac imaging procedure						At least 1 cardiac procedure/surgery						At least 1 vascular procedure					
	Bivariate		Multivariable: complete case*,†		Multivariable: multiple imputation*,‡		Bivariate		Multivariable: complete case*,†		Multivariable: multiple imputation*,‡		Bivariate		Multivariable: complete case*,†		Multivariable: multiple imputation*,‡	
	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value
Age, y, at first qualifying encounter‡	1.00 (0.99–1.01)	0.7652	1.00 (0.99–1.01)	0.8861	1.00 (0.99–1.01)	0.8911	1.00 (0.97–1.03)	0.9781	1.00 (0.97–1.03)	0.9954	1.00 (0.97–1.03)	0.8690	1.01 (0.97–1.05)	0.6054	1.00 (0.97–1.04)	0.8667	1.00 (0.97–1.04)	0.8126
Sex‖																		
Male	…		…		…		…		…		…		…		…		…	
Female	0.98 (0.94–1.03)	0.4976	0.98 (0.94–1.03)	0.5182	0.99 (0.94–1.03)	0.5495	0.95 (0.83–1.08)	0.4150	0.93 (0.82–1.07)	0.3126	0.93 (0.81–1.06)	0.2534	0.93 (0.78–1.11)	0.4027	0.92 (0.77–1.11)	0.3913	0.90 (0.76–1.07)	0.2390
Insurance status¶																		
Any public	0.92 (0.88–0.97)	0.0012	0.90 (0.86–0.94)	<0.0001	0.89 (0.84–0.93)	<0.0001	1.27 (1.11–1.44)	0.0004	0.93 (0.82–1.07)	0.3191	0.92 (0.81–1.06)	0.2505	1.32 (1.11–1.58)	0.0018	0.89 (0.74–1.07)	0.2113	0.89 (0.74–1.06)	0.1936
Private (no public)	…		…		…		…		…		…		…		…		…	
None	0.85 (0.66–1.09)	0.1915	0.86 (0.67–1.10)	0.2292	0.84 (0.64–1.09)	0.1797	0.73 (0.33–1.63)	0.4443	0.89 (0.40–2.00)	0.7860	0.86 (0.38–1.94)	0.7236	0.45 (0.11–1.81)	0.2609	0.58 (0.14–2.34)	0.4446	0.54 (0.13–2.17)	0.3850
CHD severity‡																		
Nonsevere	…		…		…		…		…		…		…		…		…	
Severe	1.12 (1.06–1.18)	<0.0001	…		…		3.3 (2.90–3.76)	<0.0001	…		…		3.35 (2.82–3.99)	<0.0001	…		…	
Charlson comorbidity index‖																		
0	…		…		…		…		…		…		…		…		…	
1	1.17 (1.1–1.24)	<0.0001	…		…		2.57 (2.21–2.99)	<0.0001	…		…		3.04 (2.48–3.73)	<0.0001	…		…	
2	1.30 (1.15–1.46)	<0.0001	…		…		5.31 (4.32–6.53)	<0.0001	…		…		6.96 (5.34–9.07)	<0.0001	…		…	
3+	1.32 (1.1–1.57)	0.0023	…		…		7.23 (5.56–9.39)	<0.0001	…		…		12.57 (9.35–16.89)	<0.0001	…		…	
Charlson comorbidity index by CHD severity																		
Severe vs nonsevere at Charlson score=0	…	…	1.07 (1.00–1.14)	0.0356	1.10 (1.04–1.17)	0.0014	…	…	3.36 (2.80–4.03)	<0.0001	3.52 (2.94–4.21)	<0.0001	…	…	4.46 (3.41–5.83)	<0.0001	4.20 (3.25–5.43)	<0.0001

(*Continued*)

Table 4. (Continued)

	At least 1 cardiac imaging procedure						At least 1 cardiac procedure/surgery						At least 1 vascular procedure					
	Bivariate		Multivariable: complete case*,†		Multivariable: multiple imputation*,‡		Bivariate		Multivariable: complete case*,†		Multivariable: multiple imputation*,‡		Bivariate		Multivariable: complete case*,†		Multivariable: multiple imputation*,‡	
	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value	PR§ (95% CI)	*P* value
Severe vs nonsevere at Charlson score=1	…	…	1.13 (1.01–1.27)	0.0370	1.15 (1.02–1.29)	0.0183	…	…	2.60 (2.03–3.31)	<0.0001	2.56 (2.01–3.26)	<0.0001	…	…	2.58 (1.87–3.56)	<0.0001	2.54 (1.85–3.48)	<0.0001
Severe vs nonsevere at Charlson Score=2	…	…	1.05 (0.83–1.33)	0.6702	1.05 (0.84–1.33)	0.6624	…	…	2.44 (1.65–3.62)	<0.0001	2.47 (1.68–3.65)	<0.0001	…	…	1.59 (0.99–2.53)	0.0526	1.62 (1.02–2.59)	0.0415
Severe vs nonsevere at Charlson score=3+	…	…	1.03 (0.72–1.46)	0.8855	1.03 (0.72–1.46)	0.8880	…	…	1.31 (0.80–2.15)	0.2633	1.33 (0.81–2.18)	0.2634	…	…	1.24 (0.72–2.13)	0.4302	1.22 (0.71–2.08)	0.4671

CHD indicates congenital heart defect; and *ICD-9-CM, International Classification of Diseases, Ninth Revision, Clinical Modification.*

*Model adjusted for all variables listed in the table; Model includes an interaction between Charlson score and CHD severity.

†Case count for specified model was n=9007.

‡Case count for specified model was n=9626.

§Prevalence ratio.

‖Case count for specified model was n=9625.

¶Case count for specified model was n=9008.

noncardiology ED or inpatient setting. Overall, during the study period, 96% of adolescents with CHD had at least 1 outpatient interaction with the health care system. These outpatient visits may be opportunities for providers to ask about the adolescent's cardiac care and refer the adolescent to specialty cardiac care, as needed. Additionally, outpatient cardiology visits did not affect the frequency of inpatient care as planned admissions for interventional and cardiac surgeries are likely associated with seeing a cardiologist. Routine outpatient cardiology visits that result in planned cardiac care and decreased ED visits may have an important impact on outcomes in these individuals which should be assessed in future studies. These findings emphasize the importance of lifelong congenital cardiac care for adolescents with CHD.

More than 1 in 5 adolescents with CHD had an unweighted CCI of ≥1. Adolescents with severe CHD had higher CCIs compared with those with nonsevere CHD, consistent with a prior study by Mackie et al in Quebec.[4] The most frequent non-CHD diagnoses were related to cardiac and respiratory diagnoses, while adolescents with severe CHD often had residual hemodynamic and arrhythmic issues (Table S4). Our study further demonstrates that adolescents with CHD and a CCI >3, compared with CCI=0, are 3 times more likely to have an ED visit, 7 times more likely to have a cardiac procedure, and 12 times more likely to have a vascular procedure in bivariate analyses. Additionally, greater CCI attenuated the associations between CHD severity and inpatient, and cardiac and vascular procedures, such that adolescents with nonsevere CHDs and CCI >3 had the same risk of these outcomes as adolescents with severe CHDs. This suggests that comorbidity burden (measured via CCI) may partially attenuate the relationship between CHD severity and likelihood of an inpatient visit. CCI includes cardiac as well as pulmonary, neurologic, renal, hepatic, and other extracardiac conditions that have been documented in individuals with CHD as they age.[33] These noncardiac comorbidities along with residual hemodynamic and electrophysiologic abnormalities increase health care usage and hospitalizations in the CHD population, especially as they reach adulthood.[4,34] Significant morbidity and mortality are associated with repeated hospitalizations.[3,35–37] As adolescents with CHDs age, it will be important to monitor for these CCI comorbidities and develop preventive and treatment strategies for cardiac as well as renal, hepatic, and other noncardiac conditions at an earlier age to mitigate the increased health care usage seen in this population.

This analysis has several limitations. The *ICD-9-CM* diagnosis code classification algorithm was not validated, but followed a prior categorization used by Marelli et al.[11] Missing data limited our analysis of other important factors associated with health care usage, such as race, ethnicity, and caregiver's level of education. Additionally, these findings are limited to adolescents who accessed health care and had a CHD code documented in a health care encounter at least once between 2011 and 2013. Therefore, these are not estimates of the percentage of adolescents with CHD or of health care usage among all adolescents with CHDs, as adolescents without a health care encounter are not included in the surveillance data, and some adolescents with a documented CHD rule-out code may have incorrectly been included. Health care usage was summarized over the 3-year surveillance period for all cases because residence/surveillance system eligibility could not be ascertained for a case b efore the first recorded encounter. Because some individuals may have contributed <3 years to surveillance if they moved into or out of the surveillance region or died, our estimates of health care usage using the 3-year window may be deflated. We compared health care usage in adolescents to national data sets instead of statewide data at each site; therefore, this may limit its comparability. National data sets take a sample of hospitals to examine health care usage that may not reflect where adolescents with CHDs may seek care. Cardiology and noncardiology provider types were not validated and could underestimate the number of cardiology visits in the study attributable to missing data on provider type at encounters or inability to link data sources with some cardiology information at sites. For example, adolescents in Utah had an overall low number of cardiology encounters, which may be attributable to pediatric cardiology encounters classified as general pediatrics. Additionally, North Carolina was excluded because of lack of provider-type encounters. Among 79 802 outpatient visits in the remaining 4 sites, 29% of these visits had an unknown provider type (Table S1). Additionally, we could not examine temporality of cardiology encounters with inpatient or ED visits. Finally, we examined associations between CCI and ED visits, but the CCI has been validated only in the inpatient setting.[15]

Adolescents with CHDs continue to have high resource usage compared with the general US adolescent population. Increased inpatient and ED visits were noted in adolescents with severe CHDs compared with nonsevere CHDs and especially among adolescents with public insurance and who lack continuous cardiology care. Adolescents with CHDs and comorbidities also showed high levels of usage. This study illustrates the ongoing significant burden of disease and the importance of ensuring continuity of care for this vulnerable population.

ARTICLE INFORMATION

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Disclosures

The authors have nothing to disclose.

Supplemental Material

Tables S1–S4

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SUPPLEMENTAL MATERIAL

Table S1. Provider types for outpatient visits overall and outpatient visits with cardiac imaging, cardiac procedures, and vascular procedures among adolescents with a documented CHD-related ICD-9-CM code in at least one healthcare encounter, 4 sites, 2011-2013*

Provider Type Description	All sites		
	All visits	Visits among severe cases	Visits among non-severe cases
Provider type for outpatient visits, n (%)			
Any Provider Type	79802	28028 (35.1)	51774 (64.9)
Cardiology Providers	7906 (9.9)	3213 (11.5)	4693 (9.1)
Non-Cardiology Providers	48685 (61.0)	16814 (60.0)	31871 (61.6)
Unknown Provider	23211 (29.1)	8001 (28.6)	15210 (29.4)
Provider type for outpatient visits with cardiac imaging, n (%)			
Any Provider Type	14296	5739 (40.1)	8557 (59.9)
Cardiology Providers	6734 (47.1)	2639 (46.0)	4095 (47.9)
Non-Cardiology Providers	5820 (40.7)	2410 (42.0)	3410 (39.9)
Unknown Provider	1742 (12.2)	690 (12.0)	1052 (12.3)
Provider type for outpatient visits with cardiac procedures, n (%)			
Any Provider Type	702	365 (52.0)	337 (48.0)
Cardiology Providers	225 (32.1)	104 (28.5)	121 (35.9)
Non-Cardiology Providers	234 (33.3)	111 (30.4)	123 (36.5)
Unknown Provider	243 (34.6)	150 (41.1)	93 (27.6)
Provider type for outpatient visits with vascular procedures, n (%)			
Any Provider Type	255	158 (62.0)	97 (38.0)
Cardiology Providers	111 (43.5)	82 (51.9)	29 (29.9)
Non-Cardiology Providers	109 (42.8)	55 (34.8)	54 (55.7)
Unknown Provider	35 (13.7)	21 (13.3)	14 (14.4)

*Note: Numbers exclude NC site due to limited provider type information

Table S2. Cardiac procedure categorization scheme			
Procedure type description	**Corresponding ICD-9-CM codes**	**Corresponding CPT codes**	**Procedure category**
Aorta	38.34, 38.44, 38.64, 39.71, 39.73, 39.78, 38.04, 38.14, 38.15, 38.16, 38.84	33417, 0001T, 0002T, 0033T, 0034T, 0035T, 0036T, 33330, 33335, 33877, 34830, 34831, 34832, 35081, 35082, 35091, 35092, 35102, 35103, 33880, 33881	Cardiac Procedure or Surgery
Cardiac Biopsy	37.25	93505	Cardiac Procedure or Surgery
Cardiac Excision or Resection	37.10, 37.11, 37.32, 37.35, 37.36, 37.37, 37.90	33416, 0024T, 33120, 33130, 33300, 33305, 33310, 33315, 33542, 33545	Cardiac Procedure or Surgery
Cardiac Imaging - Invasive Cath	88.50, 88.58, 37.21, 37.22, 37.23, 88.52, 88.53, 88.54, 88.55, 88.56, 88.57, 37.28	36013, 75756, 93501, 93508, 93510, 93511, 93514, 93524, 93526, 93527, 93528, 93529, 93530, 93531, 93532, 93533, 93539, 93540, 93541, 93542, 93543, 93544, 93545, 93555, 93556, 93561, 93562, 93571, 93572, 93662	Cardiac Procedure or Surgery
Cardiac Imaging - Noninvasive CT or MRI	88.92	71275, 75552, 75553, 75554, 75555, 75556	Cardiac Imaging Procedure
Cardiac Imaging - Noninvasive Echo	88.72	76825, 76826, 76827, 76828, 76930, 76932, 93303, 93304, 93307, 93308, 93312, 93313, 93314, 93315, 93316, 93317, 93318, 93320, 93321, 93325, 93350	Cardiac Imaging Procedure
Cardiac Imaging - Nuclear		78465, 78468, 78469, 78472, 78473, 78481, 78483, 78494, 78496, 78456, 78460, 78464, 78466, 78499	Cardiac Imaging Procedure
Cardioversion	99.61, 99.62, 99.69	92961, 92960, G0166	Cardiac Procedure or Surgery
Conduit or Baffle	35.91, 35.92, 35.93, 35.94	33404	Cardiac Procedure or Surgery

ECMO	39.61, 39.65	33960, 33961, 36822	Cardiac Procedure or Surgery
EKG	89.51, 89.52, 89.54, 89.50	93615, 93616, S3902, 93000, 93005, 93010, 93012, 93014, 93025, 93040, 93041, 93042, S9025, 93224, 93225, 93226, 93227, 93230, 93231, 93232, 93233, 93235, 93236, 93237, 93268, 93270, 93271, 93272, 93278, 93724	Cardiac Imaging Procedure
Electrophysiology Procedure	37.33, 37.34, 37.26, 37.27	33250, 33251, 33253, 33261, 93600, 93602, 93603, 93609, 93610, 93612, 93613, 93618, 93619, 93620, 93621, 93622, 93623, 93624, 93631, 93640, 93641, 93642, 93701, 93736, 93650, 93651, 93652, 93650, 93651, 93652	Cardiac Procedure or Surgery
Heart Transplant	33.6, 37.5, 37.51	33940, 33930, 33935, 33945	Cardiac Procedure or Surgery
Loop		33282, 33284, 93727	Cardiac Procedure or Surgery
Other	37.4, 37.49, 37.99, 39.62, 39.63, 39.66, 37.29, 37.92, 39.96, 39.97	33999	Cardiac Procedure or Surgery
Pacemaker or Pacing	89.45, 89.46, 89.47, 89.48, 89.49, 00.50, 00.51, 00.52, 00.53, 00.54, 00.56, 00.57, 17.51, 17.52, 37.70, 37.71, 37.72, 37.73, 37.74, 37.75, 37.76, 37.77, 37.78, 37.79, 37.80, 37.81, 37.82, 37.83, 37.85, 37.86, 37.87, 37.89, 37.94, 37.95, 37.96, 37.97, 37.98, 39.64, 39.82, 39.83, 39.84, 39.85, 39.86, 39.87, 39.88, 39.89, 37.20, 38.26	33200, 33201, 33206, 33207, 33208, 33210, 33211, 33212, 33213, 33214, 33215, 33216, 33217, 33218, 33220, 33222, 33223, 33224, 33225, 33226, 33233, 33234, 33235, 33236, 33237, 33238, 33240, 33241, 33243, 33244, 33245, 33246, 33249, 92953, 93731, 93732, 93733, 93734, 93735, 93741, 93742, 93743, 93744	Cardiac Procedure or Surgery
Percutaneous Coronary Intervention (PCI)	00.24, 00.66, 17.55, 36.01, 36.02, 36.05, 36.04, 36.06, 36.07	92973, 92980, 92981, 92982, 92984, 92995, 92996, G0290, G0291, 92978, 92979	Cardiac Procedure or Surgery
Pericardium	37.12, 37.31, 37.24, 37.0, 37.93	32658, 32659, 32660, 32661, 33015, 33020, 33025, 33030, 33031, 33050, 33010, 33011	Cardiac Procedure or Surgery

Repair of Congenital Vascular		33606, 33802, 33803, 33820, 33822, 33824, 33840, 33845, 33851, 33852, 33853, 33860, 33861, 33863, 33870, 33875, 33690, 33788, 33800, 33925, 33926	Cardiac Procedure or Surgery
Repair of Intracardiac CHD	35.41, 35.42, 35.50, 35.51, 35.52, 35.53, 35.54, 35.55, 35.60, 35.61, 35.62, 35.63, 35.70, 35.71, 35.72, 35.73, 35.81, 35.82, 35.83, 35.84, 35.95, 35.98	33414, 33415, 33476, 33684, 33732, 33920, 33608, 33610, 33611, 33612, 33615, 33617, 33619, 33641, 33645, 33647, 33660, 33665, 33670, 33681, 33688, 33692, 33694, 33697, 33702, 33710, 33720, 33722, 33730, 33735, 33736, 33737, 33770, 33771, 33774, 33775, 33776, 33777, 33778, 33779, 33780, 33781, 33786, 33813, 33814, 33918, 33919, 33924, 33917, 33922	Cardiac Procedure or Surgery
Repair of Peripheral Vascular		34501, 34502, 34510, 34530, 34800, 34802, 34804, 34808, 34812, 34813, 34820, 34825, 34826, 34833, 34834, 34900, 35011, 35013, 35021, 35022, 35045, 35111, 35112, 35121, 35122, 35131, 35132, 35141, 35142, 35151, 35152, 35161, 35162, 35182, 35184, 35189, 35190, 35201, 35206, 35207, 35211, 35216, 35221, 35226, 35236, 35241, 35246, 35251, 35256, 35266, 35271, 35276, 35281, 35286, 35311, 35321, 35331, 35341, 35351, 35450, 35452, 35458, 35460, 35471, 35472, 35475, 35476, 35480, 35481, 35484, 35490, 35491, 35494, 35500, 35572, 35681, 35682, 35683, 36470, 36471	Cardiac Procedure or Surgery
Resuscitation	99.60, 99.63, 99.64, 37.91	32160, 92950	Cardiac Procedure or Surgery

Septal Cath Procedure		92992, 92993, 93580, 93581	Cardiac Procedure or Surgery
Shunt	39.21, 39.23	33332, 33750, 33755, 33762, 33764, 33766, 33767	Cardiac Procedure or Surgery
Stress Test	89.41, 89.42, 89.43, 89.44	93015, 93016, 93017, 93018, Q0035, S3904	Cardiac Imaging Procedure
Surgical Coronary Revascularization	36.10, 36.11, 36.12, 36.13, 36.14, 36.15, 36.16, 36.17, 36.19, 36.2, 36.3, 36.31, 36.32, 36.33, 36.34, 36.39, 36.03, 36.09, 36.91, 36.99	33500, 33501, 33502, 33503, 33504, 33505, 33506, 33572, 33508,	Cardiac Procedure or Surgery
Thrombolysis		33910, 33915, 33916, 34051, 34101, 34111, 34151, 34401, 34490	Cardiac Procedure or Surgery
Tilt		93660	Cardiac Imaging Procedure
Valve Procedure	35.00, 35.01, 35.02, 35.03, 35.04, 35.10, 35.11, 35.12, 35.13, 35.14, 35.96, 35.97, 35.99, 35.31, 35.32, 35.33, 35.34, 35.35, 35.39	33400, 33401, 33403, 33420, 33422, 33425, 33426, 33427, 33460, 33463, 33464, 33468, 33470, 33471, 33472, 33474, 33478, 33496, 33600, 33602, 92986, 92986, 92987, 92987, 92990, 92990	Cardiac Procedure or Surgery
Valve Replacement	35.05, 35.06, 35.07, 35.08, 35.09, 35.20, 35.21, 35.22, 35.23, 35.24, 35.25, 35.26, 35.27, 35.28	33405, 33406, 33410, 33411, 33412, 33413, 33430, 33465, 33475, 33361, 33362, 33363, 33364, 33365, 0318T, 33366, 33477, 00151	Cardiac Procedure or Surgery
Vascular - Intracranial	38.11, 38.12, 39.28, 38.01, 38.02, 38.31, 38.32, 38.41, 38.42, 38.51, 38.52, 38.61, 38.62, 38.81, 38.82, 39.72, 39.74, 39.75, 39.76, 39.81		Vascular Procedure

Vascular - Peripheral	38.59, 39.25, 39.29, 39.0, 39.1, 39.22, 39.24, 39.26, 39.93, 38.08, 38.18, 00.40, 00.41, 00.42, 00.43, 00.44, 00.45, 00.46, 00.47, 00.48, 00.55, 17.56, 17.71, 38.00, 38.03, 38.05, 38.06, 38.07, 38.09, 38.10, 38.13, 38.30, 38.33, 38.35, 38.36, 38.37, 38.38, 38.39, 38.40, 38.43, 38.45, 38.46, 38.47, 38.48, 38.49, 38.50, 38.53, 38.55, 38.57, 38.60, 38.63, 38.65, 38.66, 38.67, 38.68, 38.69, 38.7, 38.80, 38.83, 38.85, 38.86, 38.87, 38.88, 38.89, 39.30, 39.31, 39.32, 39.41, 39.49, 39.50, 39.51, 39.52, 39.53, 39.54, 39.55, 39.56, 39.57, 39.58, 39.59, 39.7, 39.77, 39.79, 39.8, 39.90, 39.91, 39.92, 39.94, 39.98, 39.99, 38.21, 38.22, 38.29, 00.60	35875, 35876, 35879, 35881, 37205, 37206, 37207, 37208, 37620, 37650, 37660, 37799, 50100, G0269, M0301, S2130, 35400, 36005, 36002, 36468, 36469	Vascular Procedure
Vascular Imaging - Invasive	88.42, 88.40, 88.43, 88.44, 88.45, 88.47, 88.49, 88.51, 88.60, 88.61, 88.62, 88.63, 88.64, 88.65, 88.66, 88.67, 88.68, 38.23, 38.24, 38.25, 38.91, 38.92, 38.93, 38.97	75605, 75625, 75630, 75743, 75746, 75825, 75827, 78445	Vascular Procedure
Vascular Imaging - Noninvasive		75635, G0288, 75741,	Vascular Procedure
Ventricular Assist Device	37.41, 37.52, 37.53, 37.54, 37.55, 37.60, 37.61, 37.62, 37.63, 37.64, 37.65, 37.66, 37.67, 37.68, 97.44	33967, 33968, 33970, 33971, 33973, 33974, 33975, 33976, 33977, 33978, 33979, 33980, 92970, 92971	Cardiac Procedure or Surgery

Table S3. Provider types for individuals with outpatient visits overall and outpatient visits involving cardiac imaging, cardiac procedures, and vascular procedures among adolescents with a documented CHD-related ICD-9-CM code in at least one healthcare encounter, 4 sites, 2011-2013*

Provider type for individuals with outpatient visits			
Provider Type Description	**All sites**		
	Overall	**Severe**	**Non-Severe**
Individuals with at least one outpatient visit	7036	1867 (26.5)	5169 (73.5)
Individuals with at least one outpatient visit with a cardiology provider	3349 (47.6)	955 (51.2)	2394 (46.3)
Individuals with at least one outpatient visit with an unknown provider type	2494 (35.4)	734 (39.3)	1760 (34.0)
Provider type for individuals with outpatient visits involving cardiac imaging			
Provider Type Description	**All sites**		
	Overall	**Severe**	**Non-Severe**
Individuals with at least one cardiac imaging outpatient visit	5843	1633 (28.0)	4210 (72.1)
Individuals with at least one cardiac imaging outpatient visit with a cardiology provider	3129 (53.6)	882 (54.0)	2247 (53.4)
Individuals with at least one cardiac imaging outpatient visit with an unknown provider type	835 (14.3)	251 (15.4)	584 (13.9)
Provider type for individuals with outpatient visits involving cardiac procedures			
Provider Type Description	**All sites**		
	Overall	**Severe**	**Non-Severe**
Individuals with at least one cardiac procedure outpatient visit	307	162 (52.8)	145 (47.2)
Individuals with at least one cardiac procedure outpatient visit with a cardiology provider	125 (40.7)	67 (41.4)	58 (40.0)
Individuals with at least one cardiac procedure outpatient visit with an unknown provider type	161 (52.4)	88 (54.3)	73 (50.3)
Provider type for individuals with outpatient visits involving vascular procedures			
Provider Type Description	**All sites**		
	Overall	**Severe**	**Non-Severe**
Individuals with at least one vascular procedure outpatient visit	163	94 (57.7)	69 (42.3)
Individuals with at least one vascular procedure outpatient visit with a cardiology provider	61 (37.4)	41 (43.6)	20 (29.0)
Individuals with at least one vascular procedure outpatient visit with an unknown provider type	34 (20.9)	21 (22.3)	13 (18.8)

*Note: Numbers exclude NC site due to limited provider type information

Table S4. Type of non-CHD diagnoses associated with Inpatient, Emergency Department and Outpatient Visits among adolescents a documented CHD-related ICD-9-CM code in at least one healthcare encounter, 5 sites, 2011-2013

Top 5 Non-CHD diagnosis codes among all visits

Diagnosis Code	Description	Frequency
799.9	Other unknown and unspecified cause of morbidity or mortality	5,312
758.0	Down's syndrome	4,927
V15.1	Personal history of surgery to heart and great vessels presenting hazards to health	4,682
314.01	Attention deficit disorder with hyperactivity	4,559
V20.2	Encounter for routine child health examination without abnormal findings	3,708

Top 5 Non-CHD diagnosis codes for inpatient visit (encounter level)

Diagnosis Code	Description	Frequency
V15.1	Personal history of surgery to heart and great vessels presenting hazards to health	911
493.9	Asthma unspecified	696
996.83	Complication heart transplant	695
518.81	Acute respiratory failure, unspecified whether with hypoxia or hypercapnia	613
427.89	Other specified cardiac dysrhythmias	607

Top 5 Non-CHD diagnosis code for ED visit (encounter level)

Diagnosis Code	Description	Frequency
786.5	Chest Pain, Unspecified	754
493.9	Asthma unspecified	502
V15.1	Personal history of surgery to heart and great vessels presenting hazards to health	388
784.0	Vascular headache, not elsewhere classified (billable)	377

780.6	Fever and other physiologic disturbances of temperature regulation	349

Top 5 Non-CHD diagnosis code for OP visits (encounter level)

Diagnosis Code	Description	Frequency
799.9	Other unknown and unspecific cause of morbidity or mortality	5,214
758.0	Down's syndrome	3,918
314.01	Attention deficit disorder with hyperactivity	4,559
V20.2	Encounter for routine child health examination without abnormal findings	3,580
V15.1	Personal history of surgery to heart and great vessels presenting hazards to health	3,325