Published in final edited form as:
Am Heart J. 2021 June ; 236: 22–36. doi:10.1016/j.ahj.2021.02.018.

Access to cardiac surgery centers for cardiac and non-cardiac hospitalizations in adolescents and adults with congenital heart defects- a descriptive case series study

Tabassum Z. Insaf, MBBS, MPH, PhD[a,b], **Kristin M. Sommerhalter, PhD**[a], **Treeva A. Jaff, BDS, MSc**[a,b], **Sherry L. Farr, MSPH, PhD**[c], **Karrie F. Downing, MPH**[c], **Ali N. Zaidi, MD**[d], **George K. Lui, MD**[e], **Alissa R. Van Zutphen, PhD**[a,b]

[a]Center for Environmental Health, New York State Department of Health, Albany, NY

[b]School of Public Health, University at Albany, Albany, NY

[c]Centers for Disease Control and Prevention, Atlanta, GA

[d]Adult Congenital Heart Disease Center, Mount Sinai Heart/Icahn School of Medicine at Mount Sinai, New York, NY

[e]Stanford University School of Medicine, Stanford, CA

Abstract

Background—Individuals with congenital heart defects (CHDs) are recommended to receive all inpatient cardiac and noncardiac care at facilities that can offer specialized care. We describe geographic accessibility to such centers in New York State and determine several factors associated with receiving care there.

Methods—We used inpatient hospitalization data from the Statewide Planning and Research Cooperative System (SPARCS) in New York State 2008–2013. In the absence of specific adult CHD care center designations during our study period, we identified pediatric/adult and adult-only cardiac surgery centers through the Cardiac Surgery Reporting System to estimate age-based specialized care. We calculated one-way drive and public transit time (in minutes) from residential address to centers using R *gmapsdistance* package and the Google Maps Distance Application Programming Interface (API). We calculated prevalence ratios using modified Poisson regression

Reprint requests: Kristin M. Sommerhalter, PhD, Center for Environmental Health, New York State Department of Health, 1203 Corning Tower, Empire State Plaza, Albany, NY 12237. kristin.sommerhalter@health.ny.gov.
Author Contribution
Tabassum Z. Insaf: Conceptualization; methodology; writing- original draft; software; formal analysis; and supervision. Kristin M. Sommerhalter: Conceptualization, methodology; writing- original draft; software; and formal analysis. Treeva A. Jaff: Writing- review and editing; and validation. Sherry L. Farr: Project administration and writing- review and editing. Karrie F. Downing: Writing- review and editing. Ali N. Zaidi: Conceptualization. George K. Lui: Conceptualization. Alissa R. Van Zutphen: Conceptualization, Funding acquisition, supervision; project administration; and writing- review and editing.

Conflict of interest
The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Supplementary materials
Supplementary material associated with this article can be found, in the online version, at doi: 10.1016/j.ahj.2021.02.018.

with model-based standard errors, fit with generalized estimating equations clustered at the hospital level and subclustered at the individual level.

Results—Individuals with CHDs were more likely to seek care at pediatric/adult or adult-only cardiac surgery centers if they had severe CHDs, private health insurance, higher severity of illness at encounter, a surgical procedure, cardiac encounter, and shorter drive time. These findings can be used to increase care receipt (especially for noncardiac care) at pediatric/adult or adult-only cardiac surgery centers, identify areas with limited access, and reduce disparities in access to specialized care among this high-risk population.

Background

A decline in mortality from congenital heart defects (CHDs), attributed to advancement in diagnostic measures and medical and surgical therapies,[1–3] has resulted in a growing population of individuals with CHDs who require lifelong care for cardiac and noncardiac comorbidities.[4–7] In recognition of the need for lifelong specialized care, the Besthesda guidelines, published in 2002, began to outline the importance of specialized care centers for individuals with CHDs.[8] In 2008, an American Heart Association (AHA) Scientific Statement recommended that individuals with CHDs start a formal transition process from pediatric to adult healthcare by age 12 with a successful transfer to adult care achieved by 18 to 21 years.[9] Recent American College of Cardiology (ACC)/AHA consensus guidelines recommend that physicians caring for individuals with CHDs should support access to care by ensuring smooth transitions for adolescents and young adults from pediatric to adult providers and should promote awareness of the need for lifelong specialized care.[7] These guidelines specifically establish that preoperative evaluation, risk assessment, and surgery for adult CHD patients should occur in regional cardiac care centers because of access to congenital cardiology care, experienced surgeons, and cardiac anesthesiologists. Although no formal accreditation for CHD care existed at the time of the study, New York State (NYS) licenses pediatric/adult cardiac surgery centers as those facilities that offer pediatric cardiac surgery to children under 18 years in addition to adults and adult-only cardiac surgery centers as facilities licensed to offer cardiac surgery only to adults ages 18 years and older.[10]

The period of adolescence and young adulthood is a cr itical per iod in CHD care. Adolescents and young adults, in the transitional period between pediatric and adult care, have been found to be at increased risk of experiencing lapses in routine cardiac care. Literature suggests that a large proportion of individuals with CHDs do not transition successfully to adult care and less than 30% of adults with CHDs are seen by appropriate specialty cardiac care providers.[11–13] Lapses in care have been linked to a number of adverse outcomes, including an increase in concomitant morbidities, a reduction in reported quality of life, and greater mortality.[14] Previous studies have suggested that proximity to care may be barrier to care, potentially resulting in such lapses.[15, 16]

The impact of patient residential location, a key factor determining adequate access to care[17, 18] on healthcare utilization,[19–22] has not been investigated extensively among people with CHDs. In a previous pilot study, Sommerhalter et al.[23] found that the highest predicted one-way travel times were among those living in rural, high-poverty areas. In addition to geographic location, individual characteristics such as socioeconomic status, age, and CHD severity; encounter level characteristics such as health insurance,[24] type of illness and its severity; and center characteristics such as teaching status and accessibility through public transport, may influence healthcare utilization among individuals with CHDs.[12, 15, 25] However, no studies have examined these factors in relation to receipt of inpatient care at a pediatric/adult or an adult-only cardiac surgery center. Recent improvements in spatial data processing capabilities and drive distance analysis now allow for vehicular travel time to be modeled more easily using a geographic information system (GIS).[26]

Objectives

We sought to determine whether adolescents and young adults with CHDs were receiving cardiac and non-cardiac inpatient care at cardiac surgery centers in NYS. Cardiac surgery centers were defined as pediatric/adult cardiac surgery centers for those under 18 years of age and pediatric/adult or adult-only cardiac surgery centers for those 18 years or older. We chose cardiac surgery centers to serve as proxies for centers offering highly specialized CHD care. We further examined associations between travel time as a potential barrier as well as other individual, encounter, and hospital level factors with receipt of inpatient care at cardiac surgery centers.

Methods

Data was collected on hospitalizations from SPARCS,[27] on cardiac surgery programs from the Cardiac Surgery in New York State Reports,[28] and on census tract level sociodemographics from the 2010 Census,[29] the 2008–2012 American Community Survey (ACS),[30] and the 2010 Rural Urban Commuting Survey.[15] Because of the sensitive nature of the data collected for this study, requests to access the hospitalization dataset may be sent to SPARCS, NYS Department of Health (sparcs.requests@health.ny.gov) from qualified researchers trained in human subject confidentiality protocols. All other data are publicly available from the referenced sources above.

Study design and participants

This retrospective observational study was approved by the NYS Department of Health Institutional Review Board. We identified cases using hospital inpatient encounter data between January 1, 2008 and December 31, 2013 from SPARCS, an all-payer reporting system in NYS. An adolescent or young adult (defined as those between 11 and 30 years of age as of January 1st, 2013) was considered to have a CHD if he or she had documentation of one or more of the following International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) codes as a primary or secondary diagnosis code in SPARCS: 648.5X, V13.65, 745.XX-747. XX, excluding 746.86 (congenital heart block), 747.32 (pulmonary arteriovenous malformation), 747.5 (absence or hypoplasia of umbilical artery), 747.6 (other anomalies of peripheral vascular system), and 747.8 (other unspecified anomalies of the circulatory system) because these codes may not be specific to CHDs.[31] A full list of eligible CHD-related diagnosis codes is included in Appendix Table A5.

Facilities

In NYS, cardiac surgery centers are designated based on criteria specified in NYS Public Health Laws Article 10 CRR-NY 709.14 and Article 10 CRR-NY 405.29.[32, 33] We identified cardiac surgery centers from 2006–2013 reports on cardiac surgery developed collaboratively by the NYS Department of Health Cardiac Services Program and the NYS Cardiac Advisory Board using data from the Cardiac Surgery Reporting System.[34] Pediatric cardiac surgery centers were licensed to offer pediatric cardiac surgery to children under 18 years. All the pediatric cardiac surgery centers were also licensed to offer adult cardiac surgery (hereafter referred to as “pediatric/adult cardiac surgery centers”). Adult cardiac surgery centers were facilities licensed to offer cardiac surgery only to adults ages 18 years and older (hereafter referred to as “adult-only cardiac surgery centers”). Because some hospitals were not licensed to conduct cardiac surgery for the entire study period, we identified the specific months/years that each cardiac surgery center was licensed to perform pediatric and/or adult cardiac surgery.

Outcome

For each clinical encounter, we calculated whether the visit occurred at a cardiac surgery center based on patient’s age at the time of the visit. If the patient was < 18, we deemed the visit to have occurred at a cardiac surgery center if the center was licensed to perform pediatric cardiac surgery at the time of admission for the encounter. Similarly, if the patient was 18 or over, the visit was deemed to have occurred at a cardiac surgery center if it was licensed to perform adult cardiac surgery at the time of admission.

Covariates

We conceptualized that covariates at individual, encounter, and facility level would act concomitantly to influence whether an individual receives care at a cardiac surgery center (Figure 1). Within each hospitalization record, we identified the admission date, age of patient, and residential address at admission.

Individual level variables—Individual level variables included sex, race/ethnicity, CHD severity, census tract poverty, and rurality. We categorized cases as severe (having required surgical or catheter intervention in the first year of life) or nonsevere using ICD-9-CM diagnosis codes aggregated across hospital inpatient encounter records for each case. If a case had at least one severe CHD ICD-9-CM diagnosis code, that case was classified as having severe CHD. Residential addresses were assigned to one of eight health service areas (HSAs), or geographical subdivisions of NYS based on address county. We then collapsed the eight HSAs into two mutually exclusive categories (New York City [NYC] and non-NYC). Census tracts corresponding to the geocoded residential addresses were identified using 2010 US Census boundary data. We used the 2010 Census and the 2008–2012 ACS to determine census tract rurality and poverty, respectively.[29, 30] In particular, we matched each census tract to its corresponding 2010 Rural-Urban Commuting Area (RUCA) code, which classifies a census tract based on its population density, urbanization, and daily commuting. Each census tract was then designated as either rural or urban. The 2008–2012 ACS was used to calculate the percent of the population living at or under the federal poverty level

(FPL) for each census tract. Based on the Census Bureau definition, we dichotomized census tracts as low poverty areas (< 20% of the population living at or under the FPL) and high poverty areas (≥ 20% of the population at or under the FPL).

Encounter level variables—Encounter level variables included age at encounter, insurance type, admission type, encounter type, and severity of illness. All Patient Refined Diagnosis Related Group (APR DRG) codes are hospitalization classifications incorporating the primary reason for hospitalization, patient severity of illness (SOI: the extent of organ system derangement or physiologic decompensation for a patient), and type of encounter (surgical or nonsurgical). We categorized the primary reason for hospitalization into mutually exclusive cardiac (includes vascular) and non-cardiac categories; and categorized APR DRG SOI as minor, moderate, major, and extreme severity. Other hospitalization encounter level variables of interest included individual's age at encounter; insurance type (private/commercial, Medicaid, Medicare, self-pay/uninsured, other, or unknown based on primary payment source); and admission type (emergency: patient requires immediate medical intervention because of a severe or life-threatening condition, urgent: patient requires immediate attention for the care and treatment of a physical or mental disorder, elective: patient condition permits adequate time to schedule the admission, other, or unknown).

Hospital level variables included proximity and teaching status. For each hospitalization, we calculated proximity from residential address to closest cardiac surgery center using the list of centers approved to conduct surgery on the corresponding admission date. We determined teaching status for each hospital using the Centers for Medicare and Medicaid Services Open Payments list of teaching hospitals for 2013.[35]

GIS Analysis

We extracted residential addresses for eligible cases from SPARCS hospital inpatient records, excluding post office boxes, addresses listed as undomiciled, and those that matched hospital addresses. Similarly, we extracted the names and addresses of the hospitals where CHD cases received inpatient care for any reason over the study period. For each hospitalization, the identified hospital was classified as a pediatric/adult cardiac surgery center, an adult-only cardiac surgery center, or not a cardiac surgery center (hereafter referred to as a "non-cardiac center") at the time of the hospitalization. We geocoded all eligible residential addresses and hospitals using ArcMap and New York State Street and Address Maintenance Program, a statewide address point database. Street level geocoding was successfully performed for 4,779 (92.4%) residential addresses then zip-code centroid geocoding was performed for the remaining 390 addresses. We successfully geocoded all hospitals at the street level.

We estimated one-way drive time (in minutes) from patient residential address at hospital inpatient encounter to 1) the hospital where the patient received care and 2) the closest cardiac surgery center. One-way drive times and one-way public transit times from patient residential address to the hospitals were estimated using the *gmapsdistance* package in R and the Google Maps Distance Application Programming Interface (API).[36] Because the Google

API retrieves times based on the date and time of the query, we restricted queries to morning and early afternoon to reflect travel times expected for daytime visits to hospitals. Transit calculations were limited to areas with public transit data available in the Google API. If an individual received care at different hospitals on different dates or moved during the study period, each unique address-hospital pair was retained in the database.

To determine whether there were disparities in geographic accessibility to cardiac surgery centers in NYS, we estimated whether travel time was associated with receipt of care at a cardiac surgery center (yes/no). Due to road network structures and traffic patterns, a center closest by straight-line distance on the map may not be the closest center when driving. We therefore used a two-step process whereby we first identified the three closest cardiac surgery centers by a straight-line distance for each patient address. We then used the *gmapsdistance package* and the Google Maps Distance Matrix API to calculate one-way drive time and one-way public transit time from each residential address to each of the three cardiac surgery centers nearest to that address. Then, we selected the center with the shortest drive time as the closest cardiac surgery center and used this drive time in the statistical analyses.

Statistical analysis

We characterized the inpatient care received by adolescent and young adults with CHDs and determined the percent of inpatient care received at cardiac surgery centers for cardiac encounters, non-cardiac encounters, as well as for surgical cardiac encounters. For cardiac and non-cardiac hospitalizations, we summarized one-way drive time and one-way public transit time to hospitals where care was received and to the closest cardiac surgery center, both overall and stratified by region-rurality and census tract poverty. Since data on drive times showed significant skew, we used median drive times as a measure of central tendency. We chose to report results including outliers to provide a more complete picture of actual travel experiences in the study population. Chi-square tests, Wilcoxon Rank-Sum tests, Kruskal Wallis tests, and Dwass, Steel, Critchlow-Fligner multiple comparison tests were used to test for significant differences across strata. Since all missing values represented less than 20% of a given variable, no imputation was made for missing data.

Multivariate analysis

To understand whether selected individual, encounter, and hospital level factors were associated with receiving care at cardiac surgery centers for all hospitalizations, we calculated prevalence ratios at the encounter level using modified Poisson regression with model-based standard errors, fit with generalized estimating equations clustered at the hospital level and sub-clustered at the individual level. We used a nested model approach to determine separate contributions and mediation effects of individual (including residential address level), encounter, and hospital level variables. We fit three models: (1) a model containing individual level factors, (2) a model containing individual and encounter level factors, and (3) a model containing individual, encounter level factors, hospital teaching status, and one-way drive time to the closest cardiac surgery center. In sensitivity analyses, we restricted to elective/urgent admissions, excluding emergency admissions, because patients may not have a choice but to travel to the closest hospital for emergency care and because emergencies may occur away from home where another cardiac surgery center is closer. We also conducted a sensitivity analysis excluding adult only centers in consideration of these not necessarily being equipped to offer specialized CHD-specific care. Finally, we assessed distance to care among transfer admissions. Continuous variables, including distance to cardiac surgery center, were log-transformed when their distribution was skewed. Since the associations between race/ethnicity, poverty, and insurance status can be complex we checked for effect modification by these variables using interaction terms in the model. All GIS and statistical analyses were performed using ArcGIS 10.3, R 3.3.2, and SAS 9.3 (SAS Institute Inc, Cary, NC).

Results

Facilities

There were 42 hospitals in NYS that met cardiac surgery center criteria during the study period (Figure 2). Of the 42 cardiac surgery centers, 11 (26.2%) were certified as pediatric/adult cardiac surgery centers, the rest are adult-only cardiac surgery centers; 36 (85.7%) were listed as teaching hospitals. All but four cardiac surgery centers (one pediatric/adult and three adult-only) were licensed for the duration of the surveillance period; one center stopped performing pediatric cardiac surgery in 2008; two others stopped performing adult cardiac surgeries in 2010 and 2013; and one center began performing adult cardiac surgeries in 2011. Individuals with CHDs sought inpatient care at 154 noncardiac centers during the study period, of which 61 (39.7%) were listed as teaching hospitals.

Characteristics of the study population

There were 4,962 individuals with CHDs in the 11 to 30-year age group during the study period. Of these, 36 individuals were excluded because they did not have a geocodable residential address or were listed as homeless. The final sample size for analysis was therefore 4,926 cases with CHD (Table I). About 53% of cases were female, 13% of cases had severe CHDs, and about half of all cases were non-Hispanic white. Cases had 5,169 unique eligible residential addresses (data not presented). Approximately 45% of these addresses were in NYC, 95.8% were in urban census tracts, and 35.1% were in high poverty census tracts.

Table II contains information on the 6,939 inpatient hospitalizations over the study period for eligible CHD cases (mean number of hospitalizations per individual: 1.4; range 1–39). Overall 70.5% of encounters among CHD cases occurred at a cardiac surgery center. Of all inpatient hospitalizations, 3,136 (45.2%) were for cardiac reasons. Among cardiac encounters, 86.8% occurred at a cardiac surgery center while only 57.2% of noncardiac encounters were at a cardiac surgery center. Overall, private/commercial insurance was the primary insurance type for most hospitalizations (69.0%). Over half of the hospitalizations were emergency admissions, and 59.5% were nonsurgical encounters. About 45% of all hospitalizations had a moderate SOI and 31% had a major SOI. A greater proportion of cardiac hospitalizations were classified as elective (53.5%) and surgical (62.2%) compared to noncardiac hospitalizations (23.3% and 22.7%, respectively; $P < .0001$).

Cardiac hospitalizations

A majority of cardiac encounters (95.7%) occurred at teaching hospitals (data not presented). Of all cardiac encounters, 86.8% occurred at a cardiac surgery center; 29.7% were at the closest cardiac surgery center, while 57.1% were at a cardiac surgery center that was not the closest (Appendix Table A1). Overall, only 10.6% of cardiac encounters occurred at centers not licensed to offer cardiac surgery; 6.9% occurred at a noncardiac center closer than the nearest cardiac surgery center and 3.7% occurred at a noncardiac center farther than the closest cardiac surgery center. Further, 97.4% of cardiac surgical hospitalizations occurred at a cardiac surgery center (data not presented). However, 24.2% of emergency cardiac encounters occurred at a noncardiac center, whereas only 2.5% of nonemergency cardiac encounters occurred at a noncardiac center (data not shown).

Table III shows the results of unadjusted and multivariate nested models predicting care receipt at a cardiac surgery center for all cardiac hospitalizations. In model 1 which includes only individual level characteristics, patients with severe CHD (aPR = 1.07), compared to nonsevere CHD, were slightly more likely to receive care at cardiac surgery centers. Non-Hispanic blacks (aPR = 0.94), compared to non-Hispanic whites, and those in non-NYC urban and rural areas (aPR = 0.95 and 0.90, respectively), compared to those residing in NYC, were slightly less likely to receive care at a cardiac surgery center.

In model 2 with individual and encounter level factors, receipt of care at a cardiac surgery center was associated with severe CHD, living in NYC, younger age at encounter, private/commercial insurance, urgent and elective encounters, surgical encounters, and major SOI. In model 3 with individual, encounter, and hospital level factors, CHD severity and non-NYC rural residence were the only individual level characteristics associated with receiving care at a cardiac surgery center. Associations for encounter level characteristics, except age at encounter, were similar to model 2. Additionally, for every 1-minute increase in one-way drive time from residential address to closest cardiac surgery center, the individual was 8% less likely to receive care at a cardiac surgery center (aPR=0.92). Individuals were also three times more likely to receive care at a cardiac surgery center if it was a teaching hospital (aPR=3.1). There were no statistically significant interactions between race/ethnicity, poverty, and insurance status. The median one-way drive time from residential address to the hospital where inpatient care was received was 32.2 minutes (range: 0.5–331.8) for cardiac hospitalizations (Table V). Median one-way drive time from residential address to the hospital was significantly shorter in NYC and urban, non-NYC areas compared to rural areas, and for high poverty areas compared to low poverty areas.

Public transit was available from the residential address to the hospital where care was received for 78.3% of the cardiac hospitalizations. Median one-way transit time was 62.0 minutes (range: 0.3–724.3) for cardiac hospitalizations. Public transit availability varied significantly by region-rurality and area poverty for both types of hospitalizations.

For cardiac hospitalizations, median one-way drive time from residential address to the closest cardiac surgery center was 20.3 minutes overall (range: 0.5–199.7) (Table V). Median one-way drive time was significantly shorter in NYC and urban, non-NYC areas compared to rural areas, and in high poverty census tracts compared to low poverty census tracts. Public transit was available from residential address to a cardiac surgery center for 79.4% of the cardiac hospitalizations. Median one-way transit time among these hospitalizations was 42.8 minutes (range: 0.3–443.2). In rural areas, public transit was only available for 7.2% of cardiac hospitalizations

Noncardiac hospitalizations

Only 56.9% of noncardiac encounters occurred at a cardiac surgery center, whereas 36.1% occurred at a center not licensed for cardiac surgery and 13.0% occurred at a noncardiac center farther than the closest cardiac surgery center. For noncardiac encounters, receipt of care at a cardiac surgery center did not differ for emergencies (36.8%) and nonemergencies (35.2%). Teaching hospitals were the site of 81.9% of encounters.

Table IV shows the results of the unadjusted and multivariate nested models predicting care receipt at a cardiac surgery center for all hospitalizations for noncardiac encounters. Overall, associations were similar, but slightly stronger for noncardiac encounters compared to cardiac encounters. In model 1, including only individual level characteristics, patients with severe CHD (aPR=1.10), compared to nonsevere CHD, were more likely to receive care at cardiac surgery centers. Those in high poverty areas were 8% less likely to receive care at a cardiac surgery center. In addition, those in non-NYC urban areas were 12% less likely and those in rural areas were 40% less likely compared to those residing in NYC, to receive care at a cardiac surgery center. In the sensitivity analysis restricted to urgent and elective cardiac encounters, excluding 3,548 emergency admissions, estimates were slightly less precise and CHD severity, insurance type, and drive time to the closest cardiac surgery center were no longer associated with receipt of care at a cardiac surgery center.

Model 2 results for noncardiac encounters were similar to that for cardiac encounters, with additional associations between receipt of care with other insurance and stronger associations with SOI. In model 3, non-Hispanic blacks and those residing in high poverty areas were significantly less likely to receive care at cardiac surgery center s. Conversely, those in non-NYC urban and rural areas were more likely to receive care at cardiac surgery centers after adjusting for hospital level variables. The associations for the other individual and encounter level variables were similar in direction but somewhat attenuated. Finally, for every 1-minute increase in drive time to a cardiac surgery center, individuals seeking care for non-cardiac conditions were 29% less likely to receive care at a cardiac surgery center. If the center was also a teaching hospital, individuals were six times more likely to receive care at that cardiac surgery center. Results were similar when restricting to urgent and elective noncardiac encounters, though census tract poverty and rurality were no longer associated with receipt of care at cardiac surgery centers. There were no statistically significant interactions between race/ethnicity, poverty, and insurance status.

The median one-way drive time from residential address to the center where inpatient care was received was 20.7 minutes (range: 0.1–384.6) for noncardiac hospitalizations (Table V). Public transit was available for 75.3% of noncardiac hospitalizations with a median transit time of 46.0 minutes (range: 1.8–749.4). In rural areas, public transit was only available for 5.3% of noncardiac hospitalizations.

Additional analysis

We conducted a sensitivity analysis with a more conservative definition of cardiac care, including only those centers licensed in both pediatric and adult cardiac surgery as cardiac surgery centers for both adolescents and adults (Appendix Tables A2 & A3). There was a maximum of 11 pediatric/adult cardiac surgical centers in our study period, all of which were large urban teaching hospitals. As expected, the effects of distance, age, and rurality status were accentuated. However, non-Hispanic Blacks and Hispanics were more likely to seek care at cardiac surgery centers for cardiac encounters compared to the larger analysis.

Additionally, we looked at cases of transfers to another hospital (Appendix Table A4). A large proportion of such cases were transferred to pediatric/adult cardiac surgical centers (68.3% of cardiac and 56.6% of noncardiac transfers). The drive times for transfers made to pediatric cardiac surgery centers were significantly higher than for transfers to hospitals without the pediatric cardiac surgery center designation.

Discussion

In a comprehensive descriptive case-series analysis of inpatient encounters in adolescents and young adults with CHDs in NYS from 2008 to 2013, we found that a large percentage of inpatient cardiac care was received at cardiac surgery centers, median drive time was under 30 minutes to the nearest cardiac surgery center, and public transit was available for the vast majority of hospitalizations. Individuals with CHDs in NYS were significantly less likely to seek care at cardiac surgery centers for nonsurgical procedures and noncardiac encounters during the study period. We further found that individuals were less likely to visit a cardiac surgery center for emergency encounters, suggesting that in emergencies patients may be admitted to the nearest hospital, even if not a licensed cardiac surgery center. Our study identified that the important predictors for access and receipt of inpatient care at cardiac surgery centers are CHD severity, residence rurality, classification of encounter as surgical or nonsurgical, drive time, and teaching status of the hospital. We found a complex association between sociodemographic factors such as race/ethnicity and socioeconomic status, hospital level characteristics, and receipt of care at a cardiac surgery center.

There is increasing evidence that children with CHDs are at increased risk of morbidity, mortality, and resource utilization as compared to those without CHDs. Recent ACC/AHA guidelines recommend that all adult patients with CHDs, regardless of CHD severity or type of procedure, should receive all inpatient care at CHD centers.[7] While there are no comparable guidelines that have been published for children with CHDs, prior investigations support the need for specialized care for all individuals with CHDs even in the setting of routine noncardiac admissions. The creation of specialized networks for all individuals with CHDs is supported by this evidence. Therefore, this investigation further explores the barriers for cardiac and noncardiac hospitalizations in children and young adults with CHD at specialized care centers. Our results are consistent with previous research in California, which found that adults with CHDs are less likely to receive care for outpatient noncardiac surgery at a CHD center.[15]

Although we found that about 89% of individuals received cardiac care at cardiac surgery centers, only 30% of these visits occurred at the closest center. In our analysis this pattern was particularly pronounced for individuals in metropolitan NYC and other urban areas with a large number of high-volume hospitals. This suggests that individuals have a greater travel burden to receiving specialized cardiac care than necessary, particularly for cardiac encounters. CHD patients who travel farther than the closest hospital may prefer higher volume hospitals for better care quality or to satisfy insurance restrictions[37]. It follows that better regionalization of care via triage to a select few high-volume hospitals in population-dense areas may result in better quality of care than the proliferations of many small-volume centers in the same area.[37, 38] In an appropriately disseminated health system model, patients could be triaged at a smaller local hospital and those needing complicated specialty care could be referred to a better equipped hospital ideally with guidance from centralized specialists. Our sensitivity analysis for transfers suggests that many cases are transferred to distant hospitals that may be better equipped to provide CHD-specific care, such as a pediatric/adult cardiac surgery center.

As with our research, previous studies have found that distance is a significant barrier to accessing care at a CHD center in both the adult and pediatric CHD populations.[15] Time required to travel to a cardiac surgery center is also an important contributor to disparities in care and familial burdens.[39] A travel time standard of 30 minutes is considered appropriate for most medical encounters.[40, 41] The median drive times to the center where cardiac care was received (32 minutes) and to the closest cardiac surgery center (20 minutes) were just above and under this standard, but there were large differences in travel times between urban and rural areas. In the urban areas of NYC, travel times were modest, and all individuals had access to public transit. However, in other urban areas of NYS, median travel times were longer and only two-thirds of encounters occurred in areas with public transit availability. In rural areas, median drive times were over an hour and very few encounters occurred in areas where public transit was a viable option. Other studies have found that, for individuals with medical conditions requiring extended and specialized modalities of care, distance to specialized care was a burden even for individuals in urban or metropolitan areas.[22, 42, 43] Longer travel times and distances to in-network providers also interfered with an individual (or their caregiver's) ability to work.[44, 45] Extended travel time may be a substantial burden on the individual and his/her family, resulting in more time off work and lost pay. Increased travel time can contribute to high out-of-pocket expenses, financial problems, employment impact, and caregiving time, which are reported more often by families of individuals with CHDs.[39] Such families were more likely to have stopped working/cut hours to care for child and/or spend greater time providing or coordinating health care visits as compared to other families with children with special health care needs.[39] For children, the need to take time off from school for clinical appointments has also been associated with a reduced quality of life.[46]

Proximity to care remains an important mediator for lack of access to specialized cardiac care in rural areas. Telemedicine or eHealth interventions such as home-monitoring, online disease-specific information, video conferencing and texting with providers may be especially useful for adolescents and adults with CHDs who need routine follow-up care and monitoring after hospitalization.[47] In rural areas, telemedicine may allow for early prehospital diagnosis through EKG and echo image transmission to a tertiary level center for a "second opinion," thus alleviating burden of travel to a specialty care center. Telemedicine may also reduce gaps in care by allowing patient remote control through wearable devices, especially in conditions such as chronic heart failure or arrhythmias. However, equitable telemedicine requires that individuals have access to stable internet service and that interpreter services are available for populations who do not speak English, as these factors may limit accessibility in the most vulnerable.[48, 49] Making travel costs reimbursable and providing options for temporary housing support near hospitals may also help ease the travel burden for these individuals and their families. Increasing such options for routine care, having a medical home (a clinical setting that serves as a central resource for a patient's ongoing medical care) and encouraging individuals with CHDs to remain in such routine care may result in better disease management due to care coordination and avoidance of unnecessary high cost, repetitive, or emergent interventions or hospitalizations.[50, 51]

In our analysis, we also found that access to care among those in rural residences improved relative to those in NYC after adjustment for teaching status and geographic proximity. This suggests that factors that contribute to hospital choice may be different in urban and rural areas.

Insurance remained a significant barrier to accessing specialized cardiac care; individuals with Medicaid or those who were uninsured were less likely to receive care at a cardiac surgery center. This may be due to restrictions on which insurance is accepted at each facility. Similar disparities have also been documented in other studies of high-need individuals requiring emergency department visits for adult congenital heart disease[52] and pediatric neurosurgical care.[53]

Disparities due to socio-economic status and race/ethnicity persisted for non-cardiac encounters, but similar disparities did not persist for cardiac encounters. Adjusting for individual level factors, non-Hispanic Blacks and those in high poverty census tracts were less likely to receive cardiac care at cardiac surgery centers than non-Hispanic whites and those in low poverty areas, but these were no longer significant after adjustment for encounter and center level factors. These findings may reflect the fact that most non-Hispanic Blacks in NYS reside in urban areas, especially NYC, which have more teaching hospitals and public transit options. Teaching hospitals are more likely to be large safety-net hospitals in urban areas that are more likely to provide care for urban poor, blacks, and Hispanics.[54] Metropolitan teaching hospitals have also been shown to have significantly higher rates of admission compared with other hospital types for complex adult CHD.[52]

As with any research using administrative data, our study has some limitations. We may have excluded individuals with CHDs whose diagnosis was not recorded for their inpatient encounter. Additionally, misclassification of CHDs can occur with use of ICD-9-CM codes. The use of administrative codes has several limitations, such as non-specificity of the codes themselves and the medical uncertainty in the assignment of the code.[55] However, our exclusive use of inpatient admission data and a relatively young patient population likely improved the validity of CHD diagnoses, even for atrial septal defect and nonsevere codes.[55, 56]

Previous studies have found that a large proportion of CHD patients experience gaps in cardiac care in early adulthood, and those with gaps are more likely to present with more severe and symptomatic illness upon return to care.[57] Further research is needed to delineate whether gaps in CHD care may increase burden of emergency care for such individuals. Our study focused on NYS during 2008–2013, which may limit the generalizability of our results for other states or time periods with different patterns of care. Specifically, our definition of specialized cardiac care was limited to licensed cardiac surgery centers in NYS and may not reflect all hospitals in the state with expertise in congenital heart disease. The mere presence of a cardiac surgical program for adults is not necessarily a marker for high quality/ specialized adult CHD care. This means that the gaps in availability of specialized care may be even worse than what our conservative definition of “specialized” care in adults is able to capture. However, we sought to examine where CHD patients received inpatient care for which guidelines have advocated the availability of cardiac surgery. We were unable to identify non-cardiac surgical specialized centers in NYS. Since there were no criteria for specialized care centers for children or adults with CHD during the study period, our definitions are a surrogate for specialized care centers with the above limitations.[58] The Adult Congenital Heart Association (ACHA) has recently started accreditation for adult congenital heart disease programs.[59] While not a factor in this analysis of data from 2008 to 2013, future studies should examine ACHA accreditation as a factor associated with hospital preference.

We were unable to determine actual time of visit. Traffic patterns may vary by time of day and may impact drive time estimates. We therefore calculated drive time based on standard office hours (weekdays between 9 AM to 5 PM). We included all NYS addresses available for the individuals in the study; however, our database did not have information on out of state moves. Finally, socioeconomic status was derived from ACS census tract estimates and may not reflect actual socioeconomic status of the individuals. However, we expect that misclassification due to measurement error would be non-differential and have a minimal impact on our findings.

To our knowledge this is one of the first comprehensive assessments of inpatient care and barriers to specialized cardiac care among adolescents and adults with CHDs in NYS. We used statewide, population-based CHD surveillance data from a large, racially/ethnically diverse population insured by different health care payers.[60] We integrated information from multiple Cardiac Surgery Reports to create a comprehensive list of specialized cardiac care centers across NYS at time of encounter for each individual. Finally, the study used rigorous GIS-based methods for determination of travel time in place of Euclidean or simple travel distance estimates.[23] Euclidean and travel distance have been extensively used in previous literature; however, they do not account for traffic patterns, speed limits, and other factors besides distance that may impact an individual’s commute.[61] Web mapping APIs, such as the Google Maps API used for this study, are becoming the more preferred option for transportation and healthcare access analyses because they can account for such factors and, therefore, provide a more realistic estimate of travel time.[61–63] Information on public transit accessibility is rarely incorporated in studies of access to care. Inability to assess public transit time and traffic patterns has been identified as a limitation in other studies of geographic accessibility,[41, 43, 53] because results are likely not generalizable to those who prefer or rely on alternative modes of transportation. Public transit may be a preferred option in metropolitan areas such as NYC but may also be the only mode of travel for socioeconomically disadvantaged groups even in areas of lesser connectivity. We tapped into a comprehensive database of public transit data in NYS and found that outside of the well-connected metropolitan area of NYC, use of public transit is not a viable option for accessing care in most of the state.

In conclusion, this study suggests that GIS methods can be employed in studies of birth defects surveillance to provide information on barriers and burdens of accessing care, including travel time. Though a large majority of adolescents and adults in NYS access highly specialized cardiac care, significant differences exist, especially in rural areas, among individuals with less severe CHDs, and among those receiving nonsurgical or noncardiac care. Since most individuals with CHDs require lifelong cardiac care, patients and their caregivers should be counseled on the best available options for their special needs, especially if these have a significant travel burden.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

The authors would like to thank Kimberly Cozzens (Program Manager at the New York States Cardiac Services Program) for her help with identifying cardiac centers and details on New York's Cardiac Services. We also would like to thank Amandus Ankobil for his help with review and formatting of the article.

Funding

This publication was supported by the Cooperative Agreement numbers CK121202 (Emerging Infections Programs), DD151506 (Surveillance of Congenital Heart Defects Across the Lifespan), and EH171702 (Enhancing Innovation and Capabilities of the Environmental Public Health Tracking Network) funded by the Centers for Disease Control and Prevention. The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

References

1. Benjamin EJ, Virani SS, Callaway CW, et al. Heart disease and stroke statistics—2018 update: a report from the American heart association. Circulation 2018;137:e67–e492. doi: 10.1161/CIR.0000000000000558. [PubMed: 29386200]
2. Gilboa SM, Salemi JL, Nembhard WN, et al. Mortality resulting from congenital heart disease among children and adults in the United States, 1999 to 2006. Circulation 2010;122:2254–63. doi: 10.1161/circulationaha.110.947002. [PubMed: 21098447]
3. Best KE, Rankin J. Long-term survival of individuals born with congenital heart disease: a systematic review and meta-analysis. J Am Heart Assoc. 2016;5. doi: 10.1161/JAHA.115.002846.
4. Hruşcă A, Căinap S, Răchişan AL, et al. Congenital heart defects and associated comorbidities −5 years of experience. HVM Bioflux 2013;5:62–5.
5. Marelli AJ, et al. Lifetime prevalence of congenital heart disease in the general population from 2000 to 2010. Circulation 2014;130:749–56. doi: 10.1161/circulationaha.113.008396. [PubMed: 24944314]
6. Ávila P, Mercier L, Dore A, et al. Adult congenital heart disease: a Growing Epidemic. Can J Cardiol. 2014;30:S410–19. doi: 10.1016/j.cjca.2014.07.749. [PubMed: 25432136]
7. Stout KK, Daniels CJ, Aboulhosn JA. 2018 AHA/ACC guideline for the management of adults with congenital heart disease: executive summary: A report of the American college of cardiology/

American Heart Association task force on clinical practice guidelines. Circulation 2019;139:e637–97. [PubMed: 30586768]

8. Webb GD, Williams, Care of the adult with congenital heart disease: introduction RG. J Am Coll Cardiol. 2001;37(5):1166. doi: 10.1016/s0735-1097(01)01280-3. [PubMed: 11300416]
9. Warnes CA, et al. ACC/AHA 2008 Guidelines for the management of adults with congenital heart disease: executive summary. Circulation 2008;118:2395–451. doi: 10.1161/CIRCULATIONAHA.108.190811. [PubMed: 18997168]
10. New York State Laws & Regulations. Section 405.29 - Cardiac Services, https://regs.health.ny.gov/content/section-40529-cardiac-services (2020).
11. Mackie AS, Ionescu-Ittu R, Therrien J, et al. Children and adults with congenital heart disease lost to follow-up: who and when? Circulation 2009;120:302–9. doi: 10.1161/CIRCULATIONAHA.108.839464. [PubMed: 19597053]
12. Mackie AS, Pilote L, Ionescu-Ittu R, et al. Health care resource utilization in adults with congenital heart disease. Am J Cardiol 2007;99:839–43. doi: 10.1016/j.amjcard.2006.10.054. [PubMed: 17350378]
13. Reid GJ, Irvine MJ, McCrindle BW, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. Pediatrics 2004;113:e197–205. doi: 10.1542/peds.113.3.e197. [PubMed: 14993577]
14. Yeung E, Kay J, Roosevelt GE, et al. Lapse of care as a predictor for morbidity in adults with congenital heart disease. Int J Cardiol 2008;125:62–5. doi: 10.1016/j.ijcard.2007.02.023. [PubMed: 17442438]
15. Maxwell BG, Maxwell TG, Wong JK. Decentralization of care for adults with congenital heart disease in the United States: a geographic analysis of outpatient surgery. PloS one 2014;9. doi: 10.1371/journal.pone.0106730.
16. Fernandes SM, Chamberlain LJ, Grady S Jr, et al. Trends in utilization of specialty care centers in California for adults with congenital heart disease. Am J Cardiol 2015;115:1298–304. doi: 10.1016/j.amjcard.2015.02.013. [PubMed: 25765587]
17. Laditka JN, Laditka SB, Probst JC. Health care access in rural areas: Evidence that hospitalization for ambulatory care-sensitive conditions in the United States may increase with the level of rurality. Health Place 2009;15:761–70. doi: 10.1016/j.healthplace.2008.12.007. [PubMed: 19217818]
18. Chan L, Hart LG, Goodman DC. Geographic access to health care for rural Medicare beneficiaries. J Rural Health 2006;22:140–6. doi: 10.1111/j.1748-0361.2006.00022.x. [PubMed: 16606425]
19. Mooney C, Zwanziger J, Phibbs CS, Schmitt S. Is travel distance a barrier to veterans' use of VA hospitals for medical surgical care? Soc Sci Med 2000:1743–55. [PubMed: 10798329]
20. LaVela SL, Smith B, Weaver FM, Miskevics SA. Geographical proximity and health care utilization in veterans with SCI&D in the USA. Soc Sci Med 2004;59:2387–99. doi: 10.1016/j.socscimed.2004.06.033. [PubMed: 15450711]
21. Johns NE, Greene Foster D, Upadhyay UD, Foster DG. Distance traveled for Medicaid-covered abortion care in California. BMC Health Serv. Res 2017;17:1–11. doi: 10.1186/s12913-017-2241-0. [PubMed: 28049468]
22. Bell N, Kidanie T, Cai B, Krause JS. Geographic variation in outpatient health care service utilization after spinal cord injury. Arch Phys Med Rehabil 2017;98:341–6. doi: 10.1016/j.apmr.2016.09.130. [PubMed: 27984029]
23. Sommerhalter KM, Insaf TZ, Akkaya-Hocagil T, et al. Proximity to pediatric cardiac surgical care among adolescents with congenital heart defects in 11 New York counties. Birth defects Res. 2017;109:1494–503. doi: 10.1002/bdr2.1129. [PubMed: 29152921]
24. Loignon C, Hudon C, Goulet E, et al. Perceived barriers to healthcare for persons living in poverty in Quebec, Canada: the EQUIhealThY project. Int J Equity health 2015;14:4–4. doi: 10.1186/s12939-015-0135-5. [PubMed: 25596816]
25. Connor JA, Gauvreau K, Jenkins KJ. Factors associated with increased resource utilization for congenital heart disease. Pediatrics 2005;116:689–95. [PubMed: 16140709]

26. Delamater PL, Messina JP, Shortridge AM, Grady SC. Measuring geographic access to health care: raster and network-based methods. Int J Health Geograph 2012;11:15. doi: 10.1186/1476-072X-11-15.

27. New York State Department of Health. Statewide Planning and Research Cooperative System (SPARCS) https://www.health.ny.gov/statistics/sparcs/ (2019).

28. New York State Department of Health. Cardiovascular Disease Data and Statistics. (2020).

29. United States Census Bureau. 2010 Census, http://www.census.gov/2010census/data/ (2010).

30. United States Census Bureau. "Summary File."2008–2012 American Community Survey, http://ftp2.census.gov/ (2013.).

31. Robbins JM, Onukwube J, Goudie A, Collins RT 2nd. How often is congenital heart disease recognized as a significant comorbidity among hospitalized adults with congenital heart disease? Int J Cardiol 2017;235:42–8. doi: 10.1016/j.ijcard.2017.02.100. [PubMed: 28279500]

32. New York State. New York Codes, Rules and Regulations, Title 10 Section 405.29 - Cardiac Services https://regs.health.ny.gov/content/section-40529-cardiac-services (2009).

33. New York State. New York Codes, Rules and Regulations, Title 10 Section 709.14 - Cardiac Services https://regs.health.ny.gov/content/section-70914-cardiac-services (2009).

34. Hannan EL, Cozzens K, King SB, Walford G, Shah NR. The New York State cardiac registries: history, contributions, limitations, and lessons for future efforts to assess and publicly report healthcare outcomes. J Amer Coll Cardiol 2012;59:2309–16. doi: 10.1016/j.jacc.2011.12.051. [PubMed: 22698487]

35. Centers for Medicare & Medicaid Services. Open Payments, < https://www.cms.gov/OpenPayments/About/Resources >(2020).

36. Melo RA, Rodriguez DT, Zarruk D. Package 'gmapsdistance' Distance and travel time between two points from Google maps, https://cran.r-project.org/web/packages/gmapsdistance/gmapsdistance.pdf (2018).

37. Welke KF, Pasquali SK, Lin P, et al. Regionalization of congenital heart surgery in the United States. Semin Thorac Cardiovasc Surg 2020;32:128–37. doi: 10.1053/j.semtcvs.2019.09.005. [PubMed: 31518703]

38. Welke KF, Pasquali SK, Lin P, et al. Theoretical model for delivery of congenital heart surgery in the United States. Ann Thorac Surg 2020. doi: 10.1016/j.athoracsur.2020.06.057.

39. McClung N, Glidewell J, Farr SL. Financial burdens and mental health needs in families of children with congenital heart disease. Congenit Heart Dis 2018;13:554–62. doi: 10.1111/chd.12605. [PubMed: 29624879]

40. Bosanac EM, Parkinson RC, Hall DS. Geographic access to hospital care: a 30-minute travel time standard. Med Care 1976;14:616–24. [PubMed: 940405]

41. Radcliff E, Delmelle E, Kirby RS, et al. Factors associated with travel time and distance to access hospital care among infants with spina bifida. Matern Child Health J 2015. doi: 10.1007/s10995-015-1820-0.

42. Spees LP, Wheeler SB, Varia M, et al. Evaluating the urban-rural paradox: The complicated relationship between distance and the receipt of guideline-concordant care among cervical cancer patients. Gynecol Oncol 2019;152:112–18. doi: 10.1016/j.ygyno.2018.11.010. [PubMed: 30442384]

43. Friedman SA, Frayne SM, Berg E, et al. Travel time and attrition from VHA care among women veterans: how far is too far? Med Care 2015;53:S15–22. doi: 10.1097/MLR.0000000000000296. [PubMed: 25767970]

44. Hall JP, Kurth NK, Gimm G, Smith S. Perspectives of adults with disabilities on access to health care after the ACA: Qualitative findings. Disabil Health J 2019. doi: 10.1016/j.dhjo.2019.01.014.

45. Williams TS, McDonald KP, Roberts SD, et al. From diagnoses to ongoing journey: parent experiences following congenital heart disease diagnoses. J Ped Psychol 2019;44:924–36. doi: 10.1093/jpepsy/jsz055.

46. Knowles RL, Day T, Wade A, et al. Patient-reported quality of life outcomes for children with serious congenital heart defects. Arch Dis Child 2014;99:413–19. [PubMed: 24406805]

47. Kauw D, Koole MA, van Dorth JR, et al. eHealth in patients with congenital heart disease: a review. Exp Rev Cardiovasc Ther 2018;16:627–34.

48. Park J, Erikson C, Han X, Iyer P. Are state telehealth policies associated with the use of telehealth services among underserved populations? Health Affairs 2018;37:2060–8. [PubMed: 30633679]

49. Zhai Y A call for addressing barriers to telemedicine: health disparities during the COVID-19 pandemic. Psychother Psychosom 2020:1–3. doi: 10.1159/000509000.

50. Brown RS, Peikes D, Peterson G, Schore J, Razafindrakoto CM. Six features of Medicare coordinated care demonstration programs that cut hospital admissions of high-risk patients. Health Affairs 2012;31:1156–66. [PubMed: 22665827]

51. Han B, Yu H, Friedberg MW. Evaluating the impact of parent-reported medical home status on children's health care utilization, expenditures, and quality: a difference-in-differences analysis with causal inference methods. Health Serv Res 2017;52:786–806. doi: 10.1111/1475-6773.12512. [PubMed: 27256684]

52. Agarwal S, Sud K, Khare S, et al. Trends in the burden of adult congenital heart disease in US emergency departments. Clin Cardiol 2016;39:391–8. doi: 10.1002/clc.22541. [PubMed: 27079279]

53. Ahmed AK, Duhaime AC, Smith TR. Geographic proximity to specialized pediatric neurosurgical care in the contiguous United States. J Neurosurg Ped 2018;21:434–8. doi: 10.3171/2017.9.peds17436.

54. Figueroa JF, Joynt KE, Zhou X, Orav EJ, Jha AK. Safety-net hospitals face more barriers yet use fewer strategies to reduce readmissions. Med Care 2017;55:229–35. doi: 10.1097/MLR.0000000000000687. [PubMed: 28060053]

55. Khan A, Ramsey K, Bollard C, et al. Limited accuracy of administrative data for the identification and classification of adult congenital heart disease. J Am Heart Assoc 2018;7. doi: 10.1161/JAHA.117.007378.

56. Rodriguez FH 3rd, Ephrem G, Gerardin JF, et al. The 745.5 issue in code-based, adult congenital heart disease population studies: Relevance to current and future ICD-9-CM and ICD-10-CM studies. Congenit Heart Dis 2018;13:59–64. doi: 10.1111/chd.12563. [PubMed: 29266726]

57. Gurvitz M, Valente AM, Broberg C, et al. Prevalence and predictors of gaps in care among adult congenital heart disease patients: HEART-ACHD (The Health, Education, and Access Research Trial). J Am Coll Cardiol 2013;61:2180–4. doi: 10.1016/j.jacc.2013.02.048. [PubMed: 23542112]

58. American Academpy of Pediatrics, Guidelines for pediatric cardiovascular centers. Pediatrics 2002;109:544–9. doi: 10.1542/peds.109.3.544. [PubMed: 11875158]

59. Adult Congenital Heart Association. ACHA ACHD Accreditation Program, < https://www.achaheart.org/provider-support/accreditation-program/ >(2020).

60. Glidewell J, Book W, Raskin-Hood C, et al. Population-based surveillance of congenital heart defects among adolescents and adults: surveillance methodology. Birth Defects Res 2018. doi: 10.1002/bdr2.1400.

61. Socharoentum M, Karimi HA. A comparative analysis of routes generated by Web Mapping APIs. Cartograph Geograph Inf Sci 2015;42:33–43.

62. Kobayashi S, Fujioka T, Tanaka Y, et al. A geographical information system using the Google Map API for guidance to referral hospitals. J Med Syst 2010;34:1157–60. doi: 10.1007/s10916-009-9335-0. [PubMed: 20703591]

63. Weiss DJ, Nelson A, Gibson HS, et al. A global map of travel time to cities to assess inequalities in accessibility in 2015. Nature 2018;553:333 https://www.nature.com/articles/nature25181#supplementary-information. doi: 10.1038/nature25181. [PubMed: 29320477]

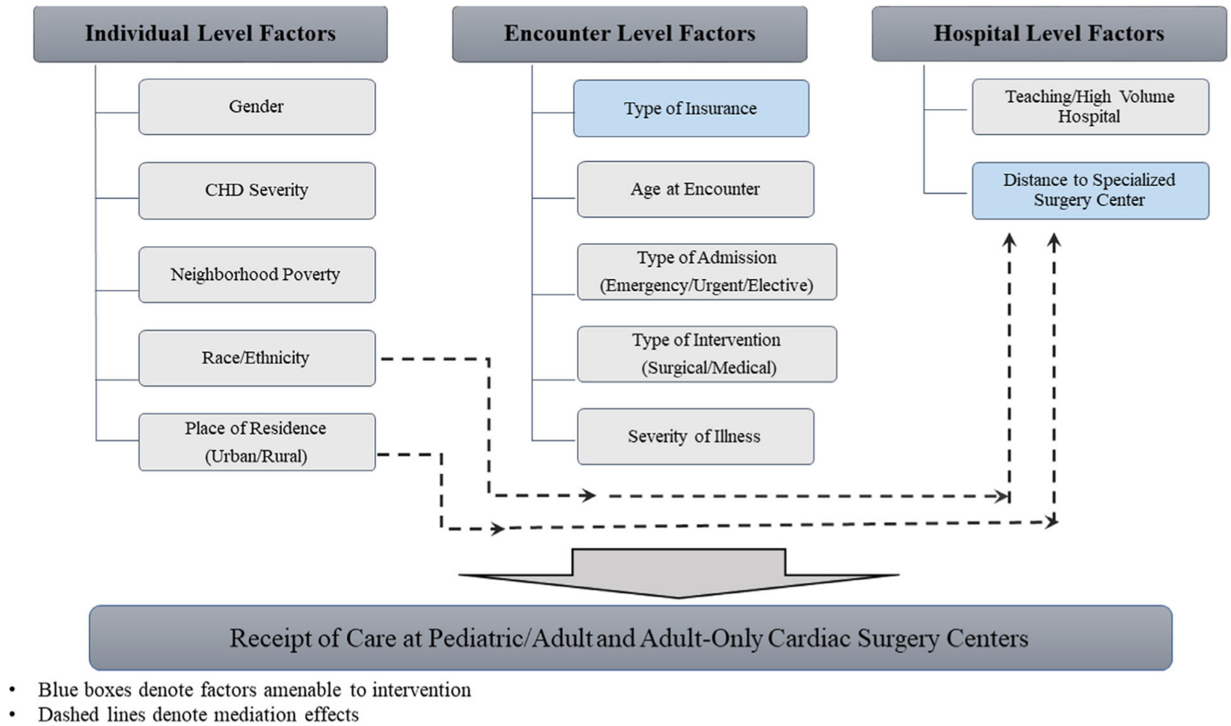

Figure 1.

Conceptual model showing individual, encounter, and hospital level factors that influence receipt of care at a cardiac surgery center

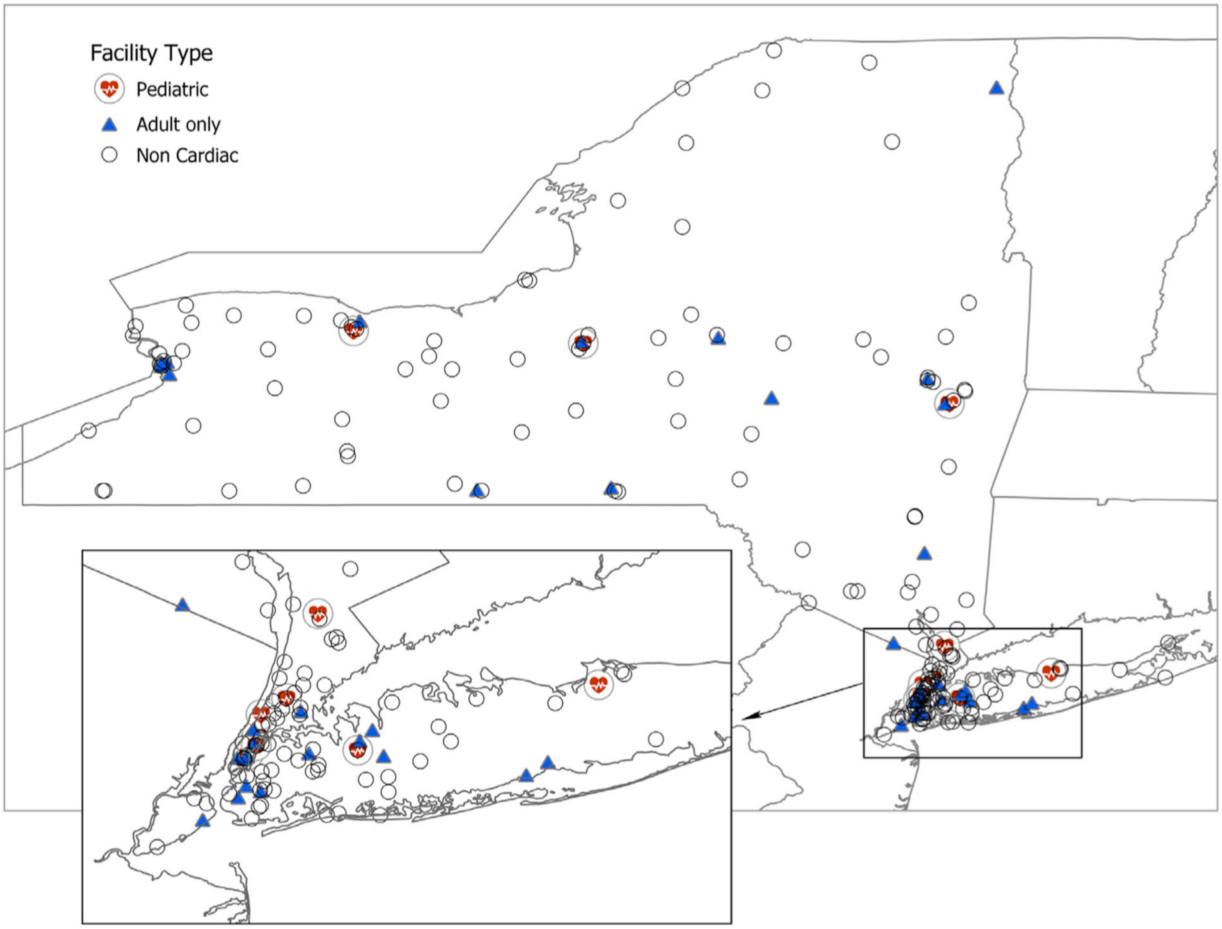

Figure 2.
Healthcare facilities visited by individuals with CHDs in New York State 2008–2013

Table I.

Characteristics of adolescents and young adults with congenital heart defects (CHDs) in New York with ≥1 hospitalization during 2008 to 2013

	***n* (%)**
Total cases	4926
Age (on January 1, 2013)	
11–15	1104 (22.4)
16–20	1141 (23.2)
21–25	1265 (25.7)
26–30	1416 (28.8)
Sex	
Female	2584 (52.5)
Male	2342 (47.5)
Race/ethnicity	
White/non-Hispanic	2431 (49.4)
Black/non-Hispanic	745 (15.1)
Other/non-Hispanic	979 (19.9)
Hispanic Origin	762 (15.5)
Unknown/missing	9 (0.2)
Congenital heart defect severity	
Nonsevere	4285 (87.0)
Severe	641 (13.0)

We identified individuals with inpatient encounters who were between the ages of 11 and 30 as of January 1, 2013. In the case summary table, we include age as of Jan 1, 2013.

Table II.

Characteristics of 6,939 inpatient hospitalizations among 4,926 adolescents and young adults with congenital heart defects (CHDs) in New York, 2008 to 2013

		Hospitalization classification		
	Total *N* (%)	**Cardiac/vascular *n* (%)**	**Noncardiac/ vascular *n* (%)**	***P* value**
Total	6939 (100)	3136 (45.2)	3803 (54.8)	
Care received at age appropriate cardiac center				
Yes	4895 (70.5)	2721 (86.8)	2174 (57.2)	< .0001
No	2044 (29.5)	415 (13.2)	1629 (42.8)	
Age at encounter (in years) *				
< 11	565 (8.1)	317 (10.1)	248 (6.5)	< .0001
11–15	1458 (21.0)	730 (23.3)	728 (19.1)	
16–20	1680 (24.2)	773 (24.7)	907 (23.9)	
21–25	1848 (26.6)	748 (23.9)	1100 (28.9)	
26–30	1343 (19.4)	560 (17.9)	783 (20.6)	
> 30	45 (0.7)	8 (0.3)	37 (1.0)	
Insurance Type				
Private/Commercial	4787 (69.0)	2360 (75.3)	2427 (63.8)	< .0001
Medicaid	1442 (20.8)	487 (15.5)	955 (25.1)	
Medicare	252 (3.6)	71 (2.3)	181 (4.8)	
Self-pay/Uninsured	277 (4.0)	143 (4.6)	134 (3.5)	
Other	160 (2.3)	66 (2.1)	94 (2.5)	
Unknown	21 (0.3)	9 (0.3)	12 (0.3)	
Admission Type				
Emergency	3548 (51.1)	1165 (37.2)	2383 (62.7)	< .0001
Urgent	798 (11.5)	278 (8.9)	520 (13.7)	
Elective	2566 (37.0)	1679 (53.5)	887 (23.3)	
Other	6 (0.1)	1 (0.0)	5 (0.1)	
Unknown	21 (0.3)	13 (0.4)	8 (0.2)	
Surgical procedure performed				
Yes	2812 (40.5)	1949 (62.2)	863 (22.7)	< .0001

	Total N (%)	Hospitalization classification: Cardiac/vascular n (%)	Hospitalization classification: Noncardiac/ vascular n (%)	P value
No	4127 (59.5)	1187 (37.9)	2940 (77.3)	
APR DRG Severity of Illness				
Minor	1204 (17.4)	887 (28.3)	317 (8.3)	< .0001
Moderate	3113 (44.9)	1212 (38.7)	1901 (50.0)	
Major	2156 (31.1)	856 (27.3)	1300 (34.2)	
Extreme	466 (6.7)	181 (5.8)	285 (7.5)	
Where hospitalization occurred				
Cardiac surgical care center	4895 (70.5)	2721 (86.8)	2174 (57.2)	< .0001
Other center	2044 (29.5)	415 (13.2)	1629 (42.8)	
Teaching hospital				
Yes	6093 (87.8)	3000 (95.66)	3093 (81.3)	< .0001
No	846 (12.2)	136 (4.34)	710 (18.7)	

We identified individuals with inpatient encounters who were between the ages of 11 and 30 as of January 1st, 2013. In the encounter summary, we include age at the time of the encounter. There may be individuals who were younger or older than the specified age range at different points in the surveillance period Abbreviations: APR DRG = All Patient Refined Diagnosis Related Group

Table III.

Prevalence ratio (PR) estimates and 95% confidence intervals (95% CI) for the association between receiving care at a cardiac surgical care center [*] and selected individual, encounter and center level characteristics, among cardiac encounters, 2008 to 2013

	Unadjusted	**Model 1 PR (95% CI)**	**Model 2[†] PR (95% CI)**	**Model 3[‡] PR (95% CI)**
Sex				
Female	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
Male	0.99 (0.97–1.01)	0.99 (0.96–1.01)	0.99 (0.97–1.01)	1.00 (0.97–1.02)
Race/ethnicity				
White/Non-Hispanic	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
Black/Non-Hispanic	0.96 (0.93–1.00)	**0.94 (0.91–0.98)**	0.99 (0.95–1.03)	0.98 (0.94–1.02)
Other/Non-Hispanic	1.02 (0.98–1.05)	1.00 (0.97–1.03)	1.02 (0.99–1.05)	1.01 (0.98–1.04)
Hispanic origin	0.99 (0.96–1.03)	0.98 (0.94–1.02)	1.00 (0.96–1.04)	0.98 (0.95–1.02)
Congenital heart defect severity				
Non-severe	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
Severe	**1.07 (1.04–1.10)**	**1.07 (1.04–1.10)**	**1.07 (1.04–1.10)**	**1.05 (1.02–1.08)**
Census tract poverty				
Low	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
High	0.99 (0.97–1.02)	**0.97 (0.94–1.00)**	0.98 (0.96–1.01)	1.00 (0.97–1.03)
Region/Census tract rurality				
NYC	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
Non-NYC, Urban	**0.93 (0.87–0.99)**	**0.95 (0.92–0.97)**	**0.95 (0.92–0.97)**	1.00 (0.97–1.03)
Non-NYC, Rural	**0.96 (0.94–0.99)**	**0.90 (0.84–0.97)**	**0.93 (0.87–1.00)**	**1.14 (1.06–1.23)**
Age at encounter (years)				
<16	1 (Reference)		1 (Reference)	1 (Reference)
16–20	**0.95(0.92–0.98)**		**0.96 (0.92–0.99)**	0.98(0.95–1.01)
21–25	**0.96 (0.93–0.99)**		1.02(0.98–1.06)	1.01 (0.97–1.05)
>25	**0.93(0.90–0.97)**		**0.96 (0.92–0.99)**	1.03 (1.00–1.07)
Insurance type				
Private/Commercial	1 (Reference)		1 (Reference)	1 (Reference)
Medicaid	**0.90 (0.87–0.93)**		**0.95 (0.91–0.98)**	**0.95 (0.92–0.99)**
Medicare	0.94 (0.87–1.02)		0.95 (0.88–1.04)	0.97 (0. 90–1.05)

	Unadjusted	Model 1 PR (95% CI)	Model 2[†] PR (95% CI)	Model 3[‡] PR (95% CI)
Self-pay/Uninsured	**0.83 (0.76–0.91)**		**0.87 (0.82–0.93)**	**0.90 (0.84–0.96)**
Other	**0.80 (0.75–0.85)**		**0.88 (0. 81–0.97)**	**0.88 (0. 80–0.96)**
Admission type				
Emergency	1 (Reference)		1 (Reference)	1 (Reference)
Urgent	**1.19 (1.14–1.24)**		**1.14 (1.09–1.19)**	**1.14 (1.09–1.20)**
Elective	**1.28 (1.25–1.32)**		**1.14 (1.10–1.19)**	**1.14 (1.09–1.18)**
Surgical encounter				
Yes	1 (Reference)		1 (Reference)	1 (Reference)
No	**0.78 (0.76–0.80)**		**0.84 (0.81–0.87)**	**0.88 (0.85–0.91)**
Severity of illness				
Minor	1 (Reference)		1 (Reference)	1 (Reference)
Moderate	**0.96 (0.94–0.99)**		1.03 (1.00–1.06)	1.03 (1.00–1.06)
Major	1.03 (0.99–1.06)		**1.05 (1.01–1.08)**	**1.04 (1.01–1.08)**
Extreme	1.01 (0.96–1.07)		1.04 (0.98–1.10)	1.04 (0.98–1.10)
Log time to closest age-appropriate cardiac center (mins)	**0.93 (0.91–0.95)**			**0.92 (0.90–0.94)**
Teaching hospital				
Yes	**3.65 (3.26–4.09)**			**3.19 (2. 85–3.58)**
No	1 (Reference)			1 (Reference)

CI = confidence interval; NYC = New York City; PR = prevalence ratio.

[*] Defined as receiving care at a center approved to perform pediatric cardiac surgery for individuals ages 5 to 18 years and at any center approved to perform cardiac surgery for individuals ages 19 to 31 years.

[†] Includes encounter level variables (surgical/non-surgical classification, admission type, severity of illness and insurance).

[‡] Includes center level variables (travel time and teaching status).

Table IV.

Prevalence ratio (PR) estimates and 95% confidence intervals (95% CI) for the association between receiving care at a cardiac surgical care center * and selected individual, encounter and center level characteristics, among non-cardiac encounters, 2008–2013

	Unadjusted	Model 1 PR (95% CI)	Model 2† PR (95% CI)	Model 3‡ PR (95% CI)
Sex				
Female	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
Male	0.96 (0.91–1.01)	0.96 (0.92–1.01)	1.02 (0.97–1.08)	1.02 (0.97–1.07)
Race/Ethnicity				
White/Non-Hispanic	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
Black/Non-Hispanic	1.02 (0.95–1.09)	0.97 (0.90–1.05)	1.02 (0.94–1.10)	**0.84 (0.78–0.91)**
Other/Non-Hispanic	**1.15 (1.08–1.22)**	1.06 (0.99–1.14)	**1.09 (1.02–1.17)**	0.98 (0.92–1.05)
Hispanic Origin	**1.10 (1.02–1.19)**	1.04 (0.96–1.13)	1.08 (0.99–1.17)	0.93 (0.86–1.00)
Congenital heart defect severity				
Non-severe	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
Severe	**1.08 (1.01–1.15)**	**1.09 (1.02–1.17)**	**1.10 (1.03–1.18)**	1.04 (0.98–1.11)
Census tract poverty				
High	0.98 (0.93–1.03)	**0.92 (0.87–0.97)**	**0.93 (0.87–0.98)**	**0.94 (0.89–1.00)**
Low	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
Region/Census tract rurality				
NYC	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
Non-NYC, Urban	**0.88 (0.84–0.93)**	**0.87 (0.82–0.92)**	**0.87(0.82–0.92)**	**1.09 (1.03–1.16)**
Non-NYC, Rural	**0.61 (0.52–0.70)**	**0.59 (0. 51–0.69)**	**0.60 (0.52–0.70)**	**1.49 (1.29–1.73)**
Age group (years)				
< 16	1 (Reference)		1 (Reference)	1 (Reference)
16–20	**1.00 (0.92–1.07)**		1.02 (0.94–1.10)	0.98 (0.92–1.06)
21–25	**1.22 (1.14–1.31)**		**1.28 (1.19–1.37)**	1.07 (1.00–1.15)
> 25	**1.26 (1.17–1.35)**		**1.31 (1.22–1.41)**	1.08 (1.00–1.16)
Insurance type				
Private/Commercial	1 (Reference)		1 (Reference)	1 (Reference)
Medicaid	**0.88 (0.82–0.93)**		**0.87 (0.82–0.93)**	**0.92 (0.87–0.98)**
Medicare	1.02 (0.92–1.14)		0.92 (0.82–1.04)	1.07 (0.96–1.20)

	Unadjusted	Model 1 PR (95% CI)	Model 2[†] PR (95% CI)	Model 3[‡] PR (95% CI)
Self-pay/Uninsured	**0.61 (0.51–0.73)**		**0.62 (0.52–0.74)**	**0.77 (0.65–0.92)**
Other	**1.23 (1.06–1.43)**		**1.32 (1.14–1.54)**	**1.21 (1.04–1.39)**
Admission type				
Emergency	1 (Reference)		1 (Reference)	1 (Reference)
Urgent	**1.12 (1.04–1.20)**		**1.11 (1.03–1.19)**	**1.09 (1.02–1.17)**
Elective	**1.16 (1.09–1.23)**		**1.13 (1.06–1.21)**	**1.16 (1.09–1.23)**
Surgical procedure performed				
Yes	1 (Reference)		1 (Reference)	1 (Reference)
No	**0.88 (0.83–0.93)**		**0.90 (0.85–0.96)**	0.96 (0.90–1.02)
Severity of illness				
Minor	1 (Reference)		1 (Reference)	1 (Reference)
Moderate	**1.09 (0.98–1.20)**		1.11 (1.00–1.22)	**1.05 (0.96–1.16)**
Major	**1.24 (1.12–1.37)**		**1.25 (1.13–1.40)**	**1.19 (1.08–1.31)**
Extreme	**1.25 (1.10–1.41)**		**1.32 (1.16–1.50)**	**1.24 (1.10–1.40)**
Log time to closest age-appropriate cardiac center (minutes)	**0.73 (0.71–0.75)**			**0.71(0.68–0.74)**
Center where care received				
Non-Teaching	1 (Reference)			1 (Reference)
Teaching	**7.41 (6.32–8.68)**			**6.37 (5.46–7.43)**

CI = confidence interval; NYC = New York City; PR = prevalence ratio.

[*] Defined as receiving care at a center approved to perform pediatric cardiac surgery for individuals ages 5–18 years and at any center approved to perform cardiac surgery for individuals ages 19 to 31 years.

[†] Includes encounter level variables (APR DRG, Admission type, severity of illness and insurance).

[‡] Includes hospital level variables (travel time and teaching status).

Table V.

One-way drive time and one-way public transit time from residential address to care center for cardiac and noncardiac hospitalizations, SPARCS 2008–2013

	Proximity to center where care was received			Proximity to closest cardiac surgical care center[‡]		
	One-way drive time (mins) median (range)	**With public transit *n* (%)**	**One-way public transit time (mins) median (range)**	**One-way drive time (mins) median (range)**	**With public transit *n* (%)**	**One-way public transit time (mins) median (range)**
	Cardiac hospitalizations					
Overall	32.2 (0.5–331.8)	2456 (78.3)	62.0 (0.3–724.3)	20.3 (0.5–199.7)	2489 (79.4)	42.8 (0.3–443.2)
Region						
NYC	29.0 (0.9–170.1)	1599 (99.8)	53.6 (0.3–317.0)	17.7 (0.8–67.5)	1603 (100.0)	35.3 (0.3–120.8)
Non-NYC, Urban	36.5 (0.5–331.8)	846 (59.5)	89.8 (0.9–724.3)	23.9 (0.5–118.3)	878 (61.7)	65.6 (0.9–443.2)
Non-NYC, Rural	78.9 (2.2–285.4)	11 (9.9)	30.5 (9.5–334.0)	67.9 (2.1–199.7)	8 (7.2)	82.4 (9.5–318.0)
Census tract poverty						
High *	25.7 (2.2–228.9)	1026 (96.1)	49.1 (2.4–403.3)	17.8 (1.8–199.7)	1028 (96.3)	34.1 (2.4–253.5)
Low †	35.6 (0.5–331.8)	1430 (69.1)	74.1 (0.3–724.3)	21.8 (0.5–152.2)	1461 (70.6)	50.8 (0.3–443.2)
	Non-cardiac hospitalizations					
Overall	20.7 (0.1–384.6)	2862 (75.3)	46.0 (1.8–749.4)	20.5 (1.3–196.5)	2906 (76.4)	40.9 (2.7–749.4)
Region						
NYC	20.1 (0.1–384.6)	1566 (99.6)	38.2 (1.8–619.6)	17.1 (1.8–78.2)	1572 (99.9)	31.5 (3.1–125.1)
Non-NYC, Urban	20.4 (1.3–318.6)	1262 (61.8)	57.6 (3.9–749.4)	23.7 (1.3–113.8)	1324 (64.8)	60.8 (2.7–749.4)
Non-NYC, Rural	45.3 (2.1–314.3)	34 (18.1)	25.3 (7.0–396.5)	76.6 (13.6–196.5)	10 (5.3)	109.9 (66.8–396.5)
Census tract poverty						
High *	15.8 (1.3–384.6)	1337 (92.8)	33.4 (2.1–619.6)	17.1 (1.8–196.5)	1323 (91.9)	31.4 (3.1–241.7)
Low †	23.3 (0.1–318.6)	1525 (64.5)	60.0 (1.8–749.4)	22.6 (1.3–151.1)	1583 (67.0)	53.8 (2.7–749.4)

NYC = New York City; SPARCS = Statewide Planning and Research Cooperative System.

For both cardiac and non-cardiac hospitalizations, differences in one-way drive times and one-way transit times across region and census tract strata are statistically significant at the group level. Select statistically significant pairwise differences have been highlighted in the text.

* ≥20% of population living at or below the Federal Poverty Level.

† < 20% of population living at or below the Federal Poverty Level.

‡Centers licensed to offer cardiac surgical care to children and adults or adults only; based on age at admission.