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# How often is congenital heart disease recognized as a significant comorbidity among hospitalized adults with congenital heart disease?

**James M. Robbins, PhD**[a], **Jennifer Onukwube, MPH**[b], **Anthony Goudie, PhD**[a], and **R. Thomas Collins II, MD**[a,c]

[a]Department of Pediatrics, University of Arkansas for Medical Sciences

[b]National Center for Immunization and Respiratory Diseases, Centers for Disease Control and Prevention

[c]Department of Internal Medicine, University of Arkansas for Medical Sciences

## Abstract

**Background—**Despite frequent life-long hemodynamic and electrophysiologic abnormalities, adults with congenital heart defects (CHDs) are often lost to medical follow-up. Using a cohort of adults with CHD receiving hospital care in Arkansas, we sought to determine how often a CHD is recognized and coded during hospital admissions.

**Methods—**Data for this study come from the Agency for Healthcare Research and Quality's Arkansas State Inpatient Database (SID) for years 2004 to 2012. Using unique identifiers that link patients across hospitalizations, we created a cohort of 3,973 patients ≥18 years old with an ICD-9 code for a CHD diagnosis noted at discharge during any hospitalization.

**Results—**These 3,973 patients had 19,638 hospitalizations. A CHD was listed as the principal diagnosis in 3% of hospitalizations, a secondary diagnosis in 22%, and no CHD was listed in 75% of hospitalizations. Among patients with a critical CHD, no critical CHD was noted in 69% of hospitalizations. Cardiovascular events (heart failure, arrhythmias, cerebrovascular accidents, embolic event, or death) occurred in 60% of hospitalizations of critical CHD patients wherein no critical CHD was recorded.

**Conclusions—**CHDs are rarely acknowledged during hospitalizations of adults with a known CHD even when cardiovascular events occur. Improved awareness, disclosure and attention to comorbid CHDs among patients and providers may improve hospital management and outcomes of cardiovascular events.

Address correspondence to: James M. Robbins, PhD, Department of Pediatrics, University of Arkansas for Medical Sciences, Arkansas Children's Hospital, 1 Children's Way, Little Rock, AR 72202, Phone-: 501 364-3300, Fax: 501-364-1552, RobbinsJamesM@uams.edu.



**Conflicts of interest**

None.

**Keywords**

adult congenital heart disease; hospitalizations; recognition; cardiovascular events; death

Congenital heart defects (CHDs) occur in 4 to 50 per 1,000 births in the U.S. (1). In Arkansas, CHDs are diagnosed in 15 per 1,000 births (2). Defects vary from minor ventricular septal defects that resolve within a few months to complex single ventricles that are almost universally fatal unless immediate surgical palliation is performed. Advances in diagnosis, pharmacotherapy, pediatric cardiac surgical techniques, and cardiovascular intensive care have improved patient survival in even the most severe forms of CHD (3, 4). Survival to adulthood is now expected in 85–90% of patients with CHD (5). It is estimated that there are 1.5 million adults living with CHDs—nearly twice as many as children with CHDs (6).

As mortality has declined, it has become increasingly important to understand the longer-term outcomes and risks to the health of adults with CHD. Though some minor CHDs surgically corrected during infancy and early childhood may pose few subsequent problems, most patients with CHD are at continued risk of residual hemodynamic and electrophysiologic abnormalities (7). Residual abnormalities in this population likely contribute to increased risk of acquired comorbid medical conditions including hypertension, obesity, chronic renal disease, hyperlipidemia, cerebrovascular accidents, atrial fibrillation, and heart failure (8).

Evidence indicates that many adults with CHD are lost to medical follow-up or experience significant lapses in care (9–11). Minimal concern with CHD as a life-long comorbid condition may place many adults with CHD at greater risk of poorer outcomes when subsequent cardiovascular or other organ system problems occur (10, 12, 13).

Admissions to the hospital represent an opportunity to monitor individuals with CHD for health risks associated with the life-long condition. When adults with CHD require hospitalization for a variety of health conditions, the CHD may be recognized as impacting the clinical management and coded as such, acknowledged in the process notes but deemed not important to the principal condition under care, or not recognized. Failure to consider a CHD in the hospital management of co-occurring illnesses may place some patients at increased risk of poor outcomes.

We use hospital discharge data to determine how often a CHD is acknowledged as a comorbid condition in the discharge record of patients known to have a CHD. We hypothesize that a CHD is more likely to be recognized and coded among younger adults with fewer competing age-related illnesses, those with more complex CHDs, and adults with co-occurring cardiovascular conditions.

## Method

### Data

Data for this study come from the Agency for Healthcare Research and Quality's Arkansas State Inpatient Database (SID) for years 2004 to 2012 (14, 15). The Arkansas SID includes information on admissions of at least 24 hours duration from all 104 acute care, rehabilitation, psychiatric and Veterans hospitals in Arkansas. In the most recent year (2012), there were 343,687 total admissions of adults ≥18 years of age to Arkansas hospitals. The SID includes up to 18 ICD-9-CM diagnoses, procedures, payer status, length of stay, patient demographic characteristics, and hospital charges.

**Revisit analyses—**Each year of the Arkansas SID includes a visitLink variable that allows the linkage of patients across hospitalizations, hospitals, and years of hospitalization (16, 17). This unique linkage feature of the Arkansas SID allowed the creation of a cohort of adult patients with a CHD diagnosis during any hospitalization over the 9 years of the study.

**Congenital heart defects—**Congenital heart defects include ICD-9-CM codes: 745.0–746.85, 746.87–746.9, 747.0–747.4. Administrative data have been shown to have excellent sensitivity (99%) and very good specificity (88%) for the detection of adult CHD from ICD-9-CM codes (18). Patient CHDs were codified using the method of Warnes and others (5). Simple CHDs include ventricle septal defects, patent ductus arteriosus, atrial septal defects, pulmonary stenosis, and aortic stenosis. ICD-9-CM codes are listed in the Appendix. Patients were coded as having a simple CHD if one of these codes was the *only* CHD diagnosis listed on any of their hospital discharge records. Individuals with more than one simple CHD ICD-9-CM code were categorized as moderate CHD. Complex or critical CHDs (CCHDs) included: hypoplastic left heart syndrome, pulmonary atresia, tetralogy of Fallot, total anomalous pulmonary venous return, transposition of the great arteries, tricuspid atresia, truncus arteriosus, double-outlet right ventricle, single ventricle, Ebstein's anomaly, coarctation of the aorta, and aortic interruption/atresia/stenosis. These CCHDs occur in 16 per 10,000 births (19). Without early recognition and medical and/or surgical intervention in infancy CCHDs nearly universally result in death. Patients were coded as having a CCHD if one or more of these codes *ever* appeared on any of their hospital discharge records. Remaining CHD patients were classified as having moderately complex CHD.

### Patient Characteristics — Clinical

**Principal diagnosis—**There are up to 18 possible diagnosis fields in the Arkansas SID. The first diagnosis listed is the principal or primary diagnosis at hospital discharge. The remaining diagnoses are listed in no order of importance and are labeled secondary diagnoses. The total number of diagnoses per hospitalization for each patient was grouped into three levels (Low: 1–2, Medium: 3–5, and High: 6 or more).

**Cardiovascular events—**Cardiovascular-related events during any hospitalization included heart failure, cardiac arrhythmia, cerebrovascular accident including transient ischemic attack, and embolic events. Death during the hospitalization was combined with these events into a composite endpoint for any cardiovascular event.

**Cardiac procedures—**Cardiac procedures included cardiovascular surgeries and cardiac catheterizations. ICD-9-CM codes for events and procedures are included in the Appendix.

## Patient Characteristics — Demographics

CHD patients were grouped by age (18–33, 34–49, 50–64, and 65 or older), gender (female and male), insurance status (public: Medicaid or Medicare, private, uninsured, and other), race/ethnicity (white, black, Hispanic, and other), and location (rural and urban). Hospital charges were adjusted for inflation to 2012 dollars using Consumer Pricing Indices for inpatient hospital services. Subsequently, charges were converted to cost data by applying a SID cost-to-charge ratio algorithm (20). Because cost data are limited to Arkansas SID 2007–2012, charge data were utilized in the multivariable analysis. Patient charges and average annual hospital volume of adult CHD cases were categorized into quartiles (quartile 1: “low”, quartile 2: “low-medium”, quartile 3: high-medium, and quartile 4: “high”).

**Comparison patients—**A random sample of patients hospitalized in Arkansas was selected from the SID. Sampled patients were ≥18 years old in 2004 and did not have a CHD diagnosis. Sampled comparison patients were stratified by year of first hospitalization. Comparison patients were sampled each year in identical numbers to CHD patients first identified with a CHD diagnosis. The revisit feature of the Arkansas SID allowed for the identification of all hospitalizations of comparison patients across the 9 years of study.

**Comparison conditions—**To understand the context of coding CHD across multiple hospitalizations of the CHD cohort where conditions other than CHD are the primary reasons for the hospitalization, rates of coding of CHD were computed for hospitalizations with select primary diagnoses including trauma, cancer, psychosis/depression, and appendicitis. Also, to compare the coding of CHD across hospitalizations, coding of diabetes and myocardial infarction across multiple hospitalizations was computed. Diabetes is a chronic condition that could be expected to impact management of other medical conditions for which a patient might be hospitalized. Myocardial infarction, a discrete event, could be expected to be considered in the management of all subsequent hospitalizations.

## Statistical analysis

Analyses were conducted at the patient and hospitalization levels, as well as hospitalizations nested within patients. Differences between CHD patients and other hospitalized patients in rates of cardiovascular events occurring during any hospitalization were calculated using a Chi-Square test. Clinical characteristics were compared among hospitalizations of CHD patients with a principal CHD diagnosis, secondary CHD diagnosis, and no CHD diagnosis by nonparametric analysis of variance test for continuous characteristics (length of stay and costs) and Cochran-Mantel-Haenszel test for categorical characteristics (cardiac procedure, and cardiovascular event). Separate analyses were performed to compare clinical characteristics among hospitalizations of simple CHD and CCHD patients.

A generalized linear mixed model was used to fit a multivariable logistic regression, accounting for hospitalizations nested within patients (random variable) to predict presence of a CHD discharge diagnosis, while controlling for patient demographics, CHD complexity,

cardiovascular events, hospital charges, total number of diagnoses, average annual hospital CHD volume, and year of first CHD diagnosis.

All analyses were performed using SAS 9.4 (Cary, N.C.) and statistical difference with a p-value <0.05 was deemed statistically significant.

## Results

A total of 3,973 individuals were admitted to Arkansas hospitals from 2004 to 2012 with a diagnosis of a CHD during any hospitalization (Table 1). The number of unique individuals first diagnosed increased from 381 in 2004 to 530 in 2012. CHD patients differed somewhat from other hospitalized patients in age, gender, and public insurance. Almost half (44%) of patients with any CHD diagnosis had only a diagnosis of a simple CHD. Of patients with only isolated simple CHD diagnoses 80% were atrial septal defects followed by ventricle septal defects (11%), pulmonary stenosis (3%), aortic stenosis (3%), and patent ductus arteriosus (2%). A CCHD was diagnosed during any hospitalization for 147 patients or 4%. Of CCHDs diagnosed, tetralogy of Fallot (29%) and coarctation of the aorta (27%) were most common followed by Ebstein's anomaly (17%), transposition of the great arteries (9%), tricuspid atresia (7%), single ventricle (7%), double-outlet ventricle (3%), and truncus arteriosus, total anomalous pulmonary venuous return, and hypoplastic left heart syndrome each at 2%.

Over half of the CHD cohort (58%) had at least one cardiac procedure (surgery or catheterization). As shown in Table 2, 12% of other hospitalized patients also had a cardiac procedure. Cardiovascular events during any hospitalization were over twice as common in CHD patients compared to other hospitalized patients (70% vs. 29%, $P < 0.0001$). CHD patients were more likely than other patients to have experienced heart failure, arrhythmias, cerebrovascular accidents, or an embolic event. In-hospital death occurred nearly twice as often in CHD patients (9% vs. 5%, $P < 0.0001$).

As shown in Table 3, during the 9-year study period, 84% of patients (3,348 of 3,973) had a single hospitalization where a CHD was diagnosed. Of the 3,973 CHD patients, 74% (n = 2,946) had at least one additional hospitalization where no CHD was noted. The CHD cohort had a total of 19,638 hospitalizations over the study period.

Table 4 presents hospital outcomes among the CHD cohort according to whether the CHD was the primary diagnosis, a secondary diagnosis, or did not appear in any of the 18 possible diagnosis fields. In panel A, among the entire cohort's 19,638 hospitalizations, a CHD was listed as the primary diagnosis in 3% of hospitalizations, a secondary diagnosis in 22%, and no CHD diagnosis was listed in 75% of hospitalizations. Costs of care and number of cardiac procedures were much greater for hospitalizations with a primary CHD diagnosis. Cardiac procedures were rarely performed during hospitalizations of patients without a CHD diagnosis (9%), but cardiovascular events occurred in almost half of hospitalizations (49%). Heart failure was noted in 28% of hospitalizations, arrhythmias in 30%, and in-hospital death in 1.7%. Cardiovascular events were significantly more likely (49% vs. 37%) among CHD patients with no CHD noted than patients with CHD as a primary diagnosis. Length of

stay was significantly longer for CHD cases with no CHD noted during the hospitalization or CHD listed as a secondary diagnosis.

Among hospitalizations of patients with simple CHD (Table 4, panel B), 77% of hospitalizations of this group had no CHD noted in the medical record. Cardiovascular events were reported during 51% of hospitalizations of those with no CHD noted, 69% of hospitalizations with CHD as a secondary diagnosis, and 37% of hospitalizations when a CHD was the primary diagnosis. Compared to hospitalizations with a primary diagnosis of CHD, costs of care were significantly lower among those hospitalizations with no CHD noted, but length of stay was significantly longer.

As shown in Table 4, panel C, no CCHD diagnosis was reported in 69% of 679 hospitalizations among patients with a known CCHD. Costs (mean = $42,026) and length of stay (mean = 13.5 days) were much higher for hospitalizations where a diagnosis of a CCHD was primary compared to hospitalizations with no documented CCHD (mean = $15,268, $P < 0.0001$, mean = 5.2 days, $P < 0.0001$). Among CCHD patients there was no difference in rates of cardiovascular events during hospitalizations between those whose CCHD was a secondary diagnosis or a CCHD diagnosis was absent.

Where CHD was not the primary diagnosis in the CHD group, including admissions for trauma, cancer, or psychosis/depression, coding of CHD as a secondary diagnosis occurred in <15% of hospitalizations. Among the cohort with CCHD, when trauma or cancer was listed as the primary diagnosis, CCHD was coded as a secondary diagnosis <13% of time. When the primary diagnosis was psychosis/depression, CCHD was coded in 24% of hospitalizations.

In contrast to CHD, patients diagnosed with diabetes during any hospitalization where almost always (90%) recognized as having diabetes during hospitalizations for other primary conditions. Similar to CHD patients, those patients diagnosed with an acute myocardial infarction were rarely (<15%) coded as having had a myocardial infarction during subsequent hospitalizations for other primary conditions.

Table 5 presents a multilevel logistic regression model of the association between presence of a CHD discharge diagnosis during any given hospitalization and demographics, type of CHD, comorbid cardiovascular conditions, patient charges and hospital volume of CHD cases. The associations are adjusted for other factors in the model of hospitalizations nested within patients. Hospitalizations where a CHD diagnosis was made were associated with younger patient age (18–33 years), private payer (compared to public), white race (compared to black), later year of first CHD diagnosis, higher quartiles of total charges and average hospital volume, and a greater number of diagnoses. Further, recognition of a CHD was more likely among patients with arrhythmias or cerebrovascular accident, but significantly less likely among patients with heart failure. Recognition of a CHD was much more likely (AOR = 2.26) among patients with a CCHD compared to a simple CHD.

## Discussion

Employing the revisit feature of the Arkansas State Inpatient Database, a cohort of patients ≥18 years old with a CHD diagnosis during any hospitalization from 2004 through 2012 was assembled. Almost 4,000 patients had nearly 20,000 hospitalizations over this period. Compared to other hospitalized patients in Arkansas, those with a CHD diagnosis were more likely to have died during a hospitalization, and had higher rates of heart failure, arrhythmias, cerebrovascular accidents, and embolic events.

Adults with CHD are known to have increased risk of acquired cardiovascular disease due to residual hemodynamic and electrophysiologic abnormalities (7). Cardiovascular events including heart failure, sudden cardiac death, and cerebrovascular accidents (along with pneumonia and cancer) have been shown to be the leading causes of death among adults with CHD (21). Heart failure and arrhythmias are associated with lower physical health-related quality of life among young adults with CHD (22). Guidelines recommend continued management of adults with CHD at an adult CHD center or by a cardiologist with a referral relationship to an adult CHD center (23). Greater attention to the risk factors for acquired conditions resulting in heart failure, cardiac arrhythmia, and cerebrovascular accidents could improve survival, as well as reduce morbidity and healthcare utilization.

Among the CHD cohort, most hospitalizations (> 70%), even among those with documented CCHDs had no CHD noted in the discharge record. This finding suggests a lack of consistent cardiology follow-up of adults with CHD as they transition from pediatric to adult care, and then reach later adulthood. Clinic-based studies have documented substantial loss to follow-up and lapses in care of adults with CHD. Gurvitz and others assessed gaps in care among patients at 12 adult CHD centers in the U.S. (9). Of patients with mild CHD, 59% had gaps in care of three years or more. Among those with severe CHD, 26% had gaps in care of three years or more. Wray et al. traced the care of 893 adults with earlier repair of tetralogy of Fallot at a single institution in London (24). A quarter (24%) had not been seen in an adult CHD center for at least 3 years, and 38% were not currently being seen by an adult CHD specialist. Mackie and others employed the Quebec physicians' claims database to determine outpatient cardiology care received by 643 adults with CHD (25, 26). Among young adults in this province with free universal access to healthcare, only 39% were seen in an outpatient cardiology setting. One in five (21%) with CCHD did not have a cardiology evaluation between age 18 and 22.

The absence of a CHD diagnosis on the great majority of hospital discharges of known CHD patients found here may be explained by administrative or coding errors, billing constraints, failure of accurate reporting by patients, compelling primary diagnoses that dwarf long-standing comorbidities, or lack of concern among providers to the pre-existing condition. It is possible that inaccurate coding of the index CHD diagnosis could explain multiple additional hospitalizations where a CHD was not noted. In preliminary analysis, just such an inaccuracy was discovered. The CCHD aortic interruption/atresia/stenosis (ICD-9 code 747.11, 747.22) was noted to occur in 400 patients, many more than the epidemiology of the condition would suggest. A closer examination determined that virtually all of those patients

were elderly and likely should have been coded with the acquired cardiac diagnosis aortic valve stenosis (ICD-9 code 424.1). These cases were deleted from the study cohort.

Absence of a CHD code among some hospitalizations requiring multiple interventions for multiple conditions may be explained by billing limitations in the United States. In these cases no further diagnoses including preexisting CHD would increase the charge to the patient for hospital care.

A CHD diagnosis also may not appear on a discharge record because the CHD was not discovered during history taking at the time of admission, or prior medical records were not available to the attending physician. Limited patient awareness of the life-long CHD diagnosis or unavailable prior medical records may account for failure to recognize a CHD even when the condition had been recognized and coded in a previous hospitalization. Adults may have limited or no knowledge of the CHD diagnosis received during childhood. In one study of patients receiving explicit care for their CHD only 61% could describe their condition in lay terms or knew the name of their heart defect (27).

The present study demonstrates that the primary admission diagnosis often takes priority over the CHD, which may not be noted or may be considered unimportant. When CHD was not the primary diagnosis, the CHD went unreported in the large majority of cases. In contrast to patients with a known CHD or myocardial infarction, a diabetes diagnosis was almost always present during hospitalizations of patients with diabetes admitted for other primary conditions. Secondary diagnoses such as diabetes represent additional conditions that require clinical evaluation, therapeutic treatment, diagnostic procedures, or result in extended length of hospital stay, or increased nursing care or monitoring. This may not be seen as the case in the setting of a history of CHD.

These findings suggest that physicians often view CHD as an acute condition requiring no further vigilance following surgical or medical management during infancy and childhood. It is likely that for many hospitalizations a pre-existing CHD was acknowledged in the process notes even if not formally coded as a comorbid condition worthy of attention. More than half of the hospitalizations with no CHD code, however, were accompanied by an adverse cardiac event or death in the hospital. This finding suggests that failure to recognize the CHD may miss important opportunities for early identification of acquired secondary cardiovascular conditions. Absence of formal recognition and vigilant management may miss smoldering disease that is disclosed only when a health crisis occurs. Greater attention to the risk posed by a comorbid CHD could reduce morbidity and health care utilization and improve survival associated with cardiovascular conditions.

Potential benefits of consistent follow-up of CHD include earlier detection of arrhythmias, heart failure and pulmonary regurgitation, all of which require treatment (11). Limited, though growing evidence suggests that failure to continue care by a CHD specialist results in poorer long-term outcomes. Yeung and colleagues followed 158 adults with CHD of moderate to severe complexity with initial evaluation at a single clinic (13). Those with lapses of care of at least 2 years were three times more likely than other patients to require urgent cardiac intervention (surgical or catheter-based). Of lapsed patients 60% presented

with new conditions of hemodynamic significance including valvar regurgitation (41%), obstructive lesions (21%), ventricular dysfunction (18%), new anatomical lesions (11%), pulmonary hypertension (5%), and coronary obstructive lesions (4%).

Consistent follow-up also appears to afford a survival advantage for adults with CHD. Adherence to scheduled clinic care was associated with better survival independent of age and disease complexity among adult CHD patients for one clinic in London (28). Among a cohort of over 70,000 adults with CHD in Quebec, care in specialized ACHD centers was associated with reduced odds of death, most primarily among patients with CCHD (29).

## Limitations

Ascertaining CHD cases from administrative data are known to have limitations (18). No independent validation of CHD diagnosis was conducted as might be available from detailed medical record review. Administrative data are based on a universal, standardized reporting system, however, that relies on professional coding rather than patient-reported diagnoses. In a manual review of over 2000 CHD cases ascertained from hospital claims, diagnostic misclassification occurred in no more than a trivial proportion (26). Administrative data are not able to measure severity of CHD beyond the diagnosis. For example, no distinction can be made between VSD that resolved soon after birth, a persistent VSD, or a VSD that was closed surgically. No measure of functional status is available, and progress notes were not available that may have indicated concern with a comorbid CHD. Patient-level factors including level of education and patient awareness of the CHD were not available. These factors may have influenced accurate disclosure of a comorbid CHD during history taking.

## Conclusions

We used the unique revisit feature of Arkansas SID to identify a cohort of adults with CHD and study their hospital care over 9 years. We noted a striking absence of acknowledgement of the CHD. We also observed that over half of hospitalizations without acknowledged CHD were associated with adverse cardiovascular outcomes including death. These results suggest that adults with CHD may be better served by improved disclosure of the CHD when hospitalized and improved awareness of the need for follow-up among referring internists, primary care physicians and hospitalists.

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## Appendix. ICD-9-CM codes

| Description of diagnosis | ICD-9-CM |
|---|---|
| *Simple congenital heart defects* | |
| Ventricle septal defects | 745.4 |

| Description of diagnosis | ICD-9-CM |
|---|---|
| Patent ductus arteriosus | 747.0 |
| Atrial septal defects | 745.5 |
| Pulmonary stenosis | 747.3; 747.31; 747.32; 747.39 |
| Aortic stenosis | 746.3 |
| *Critical congenital heart defects* | |
| Hypoplastic left heart syndrome | 746.7 |
| Pulmonary atresia | 746.01 |
| Tetralogy of Fallot | 745.2 |
| Total anomalous pulmonary venous return | 747.41 |
| Transposition of the great artery | 745.10 |
| Tricuspid Atresia | 746.1 |
| Truncus arteriosus | 745.0 |
| Double-outlet ventricle | 745.11 |
| Single ventricle | 745.3 |
| Ebstein's anomaly | 746.2 |
| Coartication of the aorta | 747.10 |
| Aortic interruption/atresia/stenosis | 747.11; 747.22 |
| *Cardiovascular events* | |
| Heart failure | 428 |
| Cardiac arrhythmias | 427 |
| Cerebrovascular accident including transient ischemic attack | 431; 433–436 |
| Embolic events | 415.1; 444; 445; 673 |
| *Cardiac Procedures* | |
| Heart valve procedures | 35.00–35.04; 351; 352; 35.99 |
| Other OR heart procedures | 353; 354; 356–358; 35.50–35.54; 35.91–35.95; 35.98; 37.33; 37.52 |
| Aortic resection; replacement or anastomosis | 38.34; 38.44; 38.64 |
| Other vascular bypass and shunt; not heart | 39.21 38.35; 38.45; 38.65; 38.84; 38.85; 39.49; |
| Other OR procedures on vessels other than head and neck | 39.56–39.59 |
| Organ transplantation (other than bone marrow, corneal, or kidney | 37.51 |
| Cardiac catheterization | 37.21–37.23; 37.26 |

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## Table 1

Characteristics of adults with congenital heart disease and other patients admitted to Arkansas hospitals from 2004 to 2012

| | CHD patients N = 3,973 | | Other hospitalized patients N = 3,973 | |
|---|---|---|---|---|
| **Characteristics** | **n** | **%** | **n** | **%** |
| Year of first CHD diagnosis | | | | |
| 2004 | 381 | 10 | 381 | 10 |
| 2005 | 333 | 8 | 333 | 8 |
| 2006 | 321 | 8 | 321 | 8 |
| 2007 | 420 | 11 | 420 | 11 |
| 2008 | 511 | 13 | 511 | 13 |
| 2009 | 489 | 12 | 489 | 12 |
| 2010 | 503 | 13 | 503 | 13 |
| 2011 | 485 | 12 | 485 | 12 |
| 2012 | 530 | 13 | 530 | 13 |
| Age in 2004 | | | | |
| 18–33 years | 643 | 16 | 975 | 25 |
| 34–49 years | 1,052 | 26 | 951 | 24 |
| 50–64 years | 1,164 | 29 | 1,012 | 25 |
| 65 and above | 1,105 | 28 | 1,035 | 26 |
| Male | 1,918 | 48 | 1,572 | 40 |
| Public insurance | 2,142 | 54 | 1,883 | 47 |
| White race | 3,444 | 87 | 3,329 | 84 |
| Rural residence | 771 | 19 | 821 | 21 |
| Critical congenital heart defect (ever) | 147 | 4 | — | — |
| Simple congenital heart defect (only) | 1,746 | 44 | — | — |
| Cardiac procedure received (ever) | 2,311 | 58 | 462 | 12 |

## Table 2

Cardiac procedures and cardiovascular events among adult CHD and other patients admitted to Arkansas hospitals from 2004 to 2012

| Outcomes | Simple congenital heart defect n = 1,746 % | Critical congenital heart defect n = 147 % | All congenital heart defect n = 3,973 % | Other hospitalized patients n = 3,973 % |
|---|---|---|---|---|
| Cardiac procedure | 54 | 39 | 58 | 12 |
| Cardiovascular events | | | | |
| Death | 10 | 12 | 9 | 5 |
| Heart failure | 38 | 47 | 36 | 13 |
| Cardiac arrhythmias | 54 | 52 | 50 | 17 |
| Cerebrovascular accident | 32 | 8 | 22 | 7 |
| Embolic event | 7 | † | 6 | 2 |
| Any event | 79 | 69 | 70 | 29 |

† Indicates number of subjects > 0 but < 10 which can not be reported in accordance with data use agreement from State Inpatient Database.

## Table 3

Hospitalizations with CHD diagnosis (Dx) by hospitalizations without CHD diagnosis among adult CHD patients admitted to Arkansas hospitals from 2004 to 2012

| | Hospitalizations with CHD Dx | | | |
|---|---|---|---|---|
| **Hospitalizations without CHD Dx** | **1** | **2** | **3+** | **Total** |
| 0 | 896 | 101 | 30 | 1,027 |
| 1 | 642 | 74 | 15 | 731 |
| 2 | 438 | 49 | 22 | 509 |
| 3 | 334 | 44 | 20 | 398 |
| 4+ | 1,038 | 185 | 85 | 1,308 |
| Total | 3,348 | 453 | 172 | 3,973 |

## Table 4

Hospitalization outcomes and cardiovascular events among adult CHD patients admitted to Arkansas hospitals from 2004 to 2012 by diagnosis category

**A. All CHDs**

| | Congenital heart defect diagnosis | | | |
|---|---|---|---|---|
| **Outcomes** | **Principal n = 588 3.0%** | **Secondary n = 4,331 22.1%** | **None n = 14,719 75.0%** | **Total n = 19,638** |
| Length of stay ǂ | 4.9 ± 0.32 | 5.8 ± 0.12 | 5.4 ± 0.06 | 5.5 ± 0.05 ** |
| Costs ǂ | $22,917 ± 1,010 | $17,496 ± 424.1 | $10,938 ± 155.5 | $12,788 ± 155.6 ** |
| Cardiac procedure | 470 (79.9) | 1,490 (34.4) | 1,330 (9.0) | 3,290 (16.8) ** |
| Cardiovascular events | | | | |
| Death * | † | 115 (2.7) | 246 (1.7) | 367 (1.9) ** |
| Heart failure * | 61 (10.4) | 1,088 (25.1) | 4,083 (27.7) | 5,232 (26.6) ** |
| Cardiac arrhythmias * | 153 (26.0) | 1,556 (35.9) | 4,336 (29.5) | 6,045 (30.8) ** |
| Cerebrovascular accident * | 43 (7.3) | 479 (11.1) | 830 (5.6) | 1,352 (6.9) ** |
| Embolic event * | † | 91 (2.1) | 197 (1.3) | 291 (1.5) ** |
| Any event * | 220 (37.4) | 2,469 (57.0) | 7,236 (49.2) | 9,925 (50.5) ** |

**B. Simple CHDs**

| | Simple congenital heart defect diagnosis | | | |
|---|---|---|---|---|
| **Outcomes** | **Principal n = 315 3.5%** | **Secondary n = 1,797 19.8%** | **None n = 6,980 76.8%** | **Total n = 9,092** |
| Length of stay ǂ | 3.1 ± 0.20 | 6.7 ± 0.21 | 5.5 ± 0.08 | 5.7 ± 0.07 ** |
| Costs ǂ | $16,433 ± 767.1 | $18,608 ± 712.3 | $10,831 ± 214.5 | $12,625 ± 223.8 ** |
| Cardiac procedure | 252 (80.0) | 264 (14.7) | 60 (0.9) | 576 (6.3) ** |
| Cardiovascular events | | | | |
| Death * | † | 57 (3.2) | 125 (1.8) | 183 (2.0) ** |
| Heart failure * | 23 (7.3) | 490 (27.3) | 1,912 (27.4) | 2,425 (26.7) ** |
| Cardiac arrhythmias * | 74 (23.5) | 738 (41.1) | 2,106 (30.2) | 2,918 (32.1) ** |
| Cerebrovascular accident * | 37 (11.5) | 378 (20.3) | 482 (6.8) | 889 (9.8) ** |
| Embolic event * | † | 57 (3.2) | 93 (1.3) | 148 (1.6) ** |
| Any event * | 113 (35.9) | 1,238 (68.9) | 3,526 (50.5) | 4,877 (53.6) ** |

**C. Critical CHDs**

| | Critical congenital heart defect diagnosis | | | |
|---|---|---|---|---|
| **Outcomes** | **Principal n = 29 4.3%** | **Secondary n = 185 27.3%** | **None n = 465 68.5%** | **Total n = 679** |
| Length of stay ǂ | 13.5 ± 4.4 | 6.6 ± 1.2 | 5.2 ± 0.3 | 6.0 ± 0.4 ** |

**C. Critical CHDs**

| Outcomes | Critical congenital heart defect diagnosis: Principal n = 29 4.3% | Secondary n = 185 27.3% | None n = 465 68.5% | Total n = 679 |
|---|---|---|---|---|
| Costs ≠ | $42,026 ± 7,409.1 | $16,881 ± 2,393.1 | $15,268 ± 2,195.1 | $17,106 ± 1,681.3 ** |
| Cardiac procedure | 17 (58.6) | 29 (15.7) | 32 (6.9) | 78 (11.5) ** |
| Cardiovascular events | | | | |
| Death * | 0 | † | 10 (2.2) | 18 (2.7) |
| Heart failure * | † | 71 (38.4) | 177 (38.1) | 257 (37.9) |
| Cardiac arrhythmias * | † | 67 (36.2) | 179 (38.5) | 255 (37.6) |
| Cerebrovascular accident * | † | † | 10 (2.2) | 15 (2.2) |
| Embolic event * | 0 | † | † | † |
| Any event * | 14 (48.3) | 112 (60.5) | 278 (59.8) | 404 (59.5) |

≠ mean ± std error reported for length of stay and costs

* frequency (percent) reported.

** $P < 0.05$.

† Indicates values > 0 but < 10 which can not be reported in accordance with data use agreement from State Inpatient Database.

## Table 5

Model predicting hospitalizations with a diagnosis of CHD among adults with CHD admitted to Arkansas hospitals from 2004 to 2012 by patient and hospital characteristics

| | Diagnosis of CHD | | | |
|---|---|---|---|---|
| **Characteristics** | **AOR** | **95% CI** | | ***P*** |
| Age | | | | |
| 18 to 33 (reference) | — | — | | — |
| 34 to 49 | 0.58 | 0.49 | 0.67 | <0.0001 |
| 50 to 64 | 0.42 | 0.36 | 0.48 | <0.0001 |
| 65+ | 0.42 | 0.36 | 0.50 | <0.0001 |
| Gender | | | | |
| Female (reference) | — | — | | — |
| Male | 0.98 | 0.90 | 1.08 | 0.6957 |
| Insurance | | | | |
| Private (reference) | — | — | | — |
| Public | 0.50 | 0.44 | 0.56 | <0.0001 |
| Uninsured | 1.05 | 0.86 | 1.29 | 0.6026 |
| Other | 1.01 | 0.81 | 1.26 | 0.9481 |
| Race/ Ethnicity | | | | |
| White (reference) | — | — | | — |
| Black | 0.78 | 0.68 | 0.90 | 0.0007 |
| Hispanic | 1.67 | 1.07 | 2.60 | 0.0225 |
| Other | 0.93 | 0.54 | 1.58 | 0.7762 |
| Rural | | | | |
| No (reference) | — | — | | — |
| Yes | 1.04 | 0.93 | 1.16 | 0.5307 |
| CHD | | | | |
| Simple only (reference) | — | — | | — |
| Other | 1.19 | 1.09 | 1.31 | 0.0002 |
| Critical | 2.26 | 1.78 | 2.86 | <0.0001 |
| Death | | | | |
| No (reference) | — | — | | — |
| Yes | 1.13 | 0.87 | 1.46 | 0.3647 |
| Heart failure | | | | |
| No (reference) | — | — | | — |
| Yes | 0.82 | 0.74 | 0.90 | <0.0001 |
| Cardiac arrhythmias | | | | |
| No (reference) | — | — | | — |
| Yes | 1.27 | 1.16 | 1.38 | <0.0001 |
| Cerebrovascular accident | | | | |
| No (reference) | — | — | | — |
| Yes | 2.23 | 1.94 | 2.56 | <0.0001 |

| | Diagnosis of CHD | | | |
|---|---|---|---|---|
| **Characteristics** | **AOR** | **95% CI** | | ***P*** |
| Embolic event | | | | |
| No (reference) | — | — | | — |
| Yes | 1.08 | 0.81 | 1.45 | 0.5891 |
| Total charges | | | | |
| Q4 — highest (reference) | — | — | | — |
| Q3 | 0.50 | 0.45 | 0.55 | <0.0001 |
| Q2 | 0.37 | 0.33 | 0.41 | <0.0001 |
| Q1 | 0.33 | 0.30 | 0.37 | <0.0001 |
| Number of diagnoses | | | | |
| High (reference) | — | — | | — |
| Medium | 0.69 | 0.62 | 0.77 | <0.0001 |
| Low | 0.30 | 0.23 | 0.39 | <0.0001 |
| CHD volume | | | | |
| Q4 — greatest (reference) | — | — | | — |
| Q3 | 0.68 | 0.60 | 0.76 | <0.0001 |
| Q2 | 0.51 | 0.45 | 0.57 | <0.0001 |
| Q1 | 0.34 | 0.30 | 0.38 | <0.0001 |

Model adjusted for year and other variables in the models

* p< 0.05 is statistically significant