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Hospitalizations, Costs, and Mortality among Infants with Critical Congenital Heart Disease: How Important Is Timely Detection?

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Abstract

BACKGROUND—Critical congenital heart disease (CCHD) was recently added to the U.S. Recommended Uniform Screening Panel for newborns. States considering screening requirements may want more information about the potential impact of screening. This study examined potentially avoidable mortality among infants with late detected CCHD and assessed whether late detection was associated with increased hospital resource use during infancy.

METHODS—This was a state-wide, population-based, observational study of infants with CCHD (*n* =3603) born 1998 to 2007 identified by the Florida Birth Defects Registry. We examined 12 CCHD conditions that are targets of newborn screening. Late detection was defined as CCHD diagnosis after the birth hospitalization. Deaths potentially avoidable through screening were defined as those that occurred outside a hospital following birth hospitalization discharge and those that occurred within 3 days of an emergency readmission.

RESULTS—For 23% (*n* =825) of infants, CCHD was not detected during the birth hospitalization. Death occurred among 20% (*n* =568/2,778) of infants with timely detected CCHD and 8% (*n* =66/825) of infants with late detected CCHD, unadjusted for clinical characteristics. Potentially preventable deaths occurred in 1.8% (*n* =15/825) of infants with late detected CCHD (0.4% of all infants with CCHD). In multivariable models adjusted for selected characteristics, late

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CCHD detection was significantly associated with 52% more admissions, 18% more hospitalized days, and 35% higher inpatient costs during infancy.

CONCLUSION—Increased CCHD detection at birth hospitals through screening may lead to decreased hospital costs and avoid some deaths during infancy. Additional studies conducted after screening implementation are needed to confirm these findings.

Keywords

heart defects; congenital; pediatrics; costs and cost analysis; birth defects surveillance

INTRODUCTION

Critical congenital heart disease (CCHD) was added to the U.S. Recommended Uniform Screening Panel for newborns in 2011 (Mahle et al., 2012). CCHD refers to congenital heart defects requiring surgery or catheter intervention during infancy. Newborns with unrecognized CCHD are at risk for cardiovascular collapse (Mahle et al., 2009). Universal screening through pulse oximetry, a noninvasive estimate of blood oxygen saturation, at birth hospitals 24 to 48 hr after birth aims to identify newborns with hypoxemia-associated CCHD who received neither a prenatal diagnosis nor a diagnosis during newborn clinical examinations (Kemper et al., 2011). Many U.S. states are considering screening mandates (www.aap.org/stateadvocacy), and evidence about the potential financial impact of screening could inform those decisions.

Previous investigations of late detected CCHD and pulse oximetry screening have largely come from Europe, where different clinical circumstances, including different rates of prenatal CCHD detection (Friedberg et al., 2009; Khoshnood et al., 2012), make it difficult to translate results to the U.S. context, and none of those studies assessed healthcare costs for infants with CCHD (Knowles et al., 2005; Massin & Dessy, 2006; de-Wahl Granelli et al., 2009; Ewer et al., 2012; Roberts et al., 2012). A large Swedish study reported 28% (*n* =28/100) of infants with ductal-dependent circulation were discharged from birth hospitals without a diagnosis in the absence of screening (de-Wahl Granelli et al., 2009). A British study reported that just 10% of infants with cyanotic conditions were discharged undiagnosed in the absence of screening (Massin and Dessy, 2006). Several British studies reported that screening is a cost-effective way to increase timely CCHD diagnoses, although those studies did not assess health or financial outcomes among infants with timely versus late detected CCHD (Knowles et al., 2005; Ewer et al., 2012; Roberts et al., 2012).

Three previous U.S. studies reported state-level, population-based estimates of late CCHD detection. Based on a comprehensive study of California death registry data from 1998 to 2004, one study extrapolated that 1.7 per 100,000 infants die annually due to missed CCHD diagnoses, defined by the absence of a recorded heart surgery before death (Chang et al., 2008). A study of New Jersey hospital discharge data from 1999 to 2004 estimated 7 per 100,000 infants with screening-detectable CCHD conditions were diagnosed after birth hospital discharge (Aamir et al., 2007). A study of hospital discharge data and death records from Wisconsin from 2002 to 2006 reported 4 infants per 100,000 births with any type of congenital heart defect either died or were readmitted to the hospital within two weeks of

birth (Ng and Hokanson, 2010). Variability in previous estimates of late detected CCHD is likely due to differences in case definition and ascertainment, local differences in pediatric practice, and study methods.

Based on new recommendations for universal newborn CCHD screening, this study aimed to estimate the potential reduction in mortality that may occur with universal screening and to estimate the financial impact of screening by comparing inpatient resource use (number of admissions, number of hospitalized days, and estimated hospital costs) among infants with timely versus late detected CCHD.

METHODS

Data Sources

This was a retrospective, population-based study of Florida resident infants with CCHD born 1998 to 2007 identified by the Florida Birth Defects Registry (FBDR). The FBDR is a passive, state-wide birth defects surveillance system that identifies infants with birth defects from multiple healthcare databases (Salemi et al., 2011, 2012). The FBDR primarily identifies infants with birth defects through hospital discharge records from Florida's Agency for Health Care Administration (AHCA). AHCA collects admission, diagnosis, and facility charge information from all Florida hospitals and associated birth and surgical centers (AHCA, 2012). AHCA does not collect information from nonhospital based birthing centers, although 99% of births in Florida occur in hospitals (MacDorman et al., 2010). The FBDR includes information from state vital statistics and thus captures infant deaths that occur outside of hospitals. The FBDR does not capture information on adopted infants or those whose mothers delivered out-of-state (Salemi et al., 2011, 2012). This study was approved by Institutional Review Boards at the Florida Department of Health, the University of North Carolina at Charlotte, and the University of South Florida.

Case Definition

Our case definition included primary and secondary targets of CCHD screening. We defined timely CCHD detection as an International Classification of Disease, 9th revision; Clinical Modification (ICD-9-CM) code for screening-detectable CCHD diagnoses identified on the infant's birth hospitalization discharge record. Seven CCHD conditions that usually present with hypoxemia are classified as primary targets for screening: hypoplastic left heart syndrome (ICD-9-CM: 746.7), pulmonary atresia (with intact septum) (746.01), dextrotransposition of the great arteries (745.10), truncus arteriosus (745.0), tricuspid atresia (TRA) (746.1), tetralogy of Fallot (745.2), and total anomalous pulmonary venous connection (747.41) (Mahle et al., 2009; Kemper et al., 2011). Other CCHD conditions that sometimes present with hypoxemia are considered secondary screening targets: coarctation/hypoplasia of aortic arch (747.10), double-outlet right ventricle (745.11), aortic interruption/atresia/hypoplasia (747.11, 747.22), Ebstein anomaly (746.2), and single ventricle (745.3) (Mahle et al., 2009; CDC, 2012; CDC, 2013). Available data did not distinguish whether infants received a pre- or postnatal diagnosis of CCHD. Infants were classified to have single CCHD (e.g., tetralogy of Fallot) or multiple CCHD (e.g., coarctation/hypoplasia of aortic arch and double-outlet right ventricle).

Inclusion criteria for this analysis were as follows: (1) infants had a CCHD ICD-9-CM code for at least one screening-detectable CCHD condition; (2) infants had a corresponding birth hospitalization discharge record with associated hospital charges from AHCA; and (3) if there was no CCHD diagnosis code on the birth hospitalization record, infants had at least one subsequent hospital admission or record of death due to any cause within the first year of life.

Transfers, Hospital Care Classification, and Expected Payer Status

We analyzed the number of hospital admissions, number of hospitalized days, and estimated hospital costs based on hospitalizations initiated, but not necessarily completed, during the newborn (<28 days) and infant (<365 days) periods. Hospitalizations were assessed as continuous episodes of hospital care, regardless of whether a transfer occurred (Colvin and Bower, 2009). Multiple admissions were assessed as one hospitalization if an infant was admitted to a hospital on the same day as discharged from a previous admission, or if the infant was admitted to a hospital one day after a previous discharge with an accompanying "transfer" code. The level of birth hospitalization nursery care (I, III, or III [highest]) (American Academy of Pediatrics, 2004) that an infant received was coded as the highest facility level if a transfer occurred. Infants' hospital discharge records identified the principal expected healthcare payer for each hospitalization as private or employer-based insurance (including TRICARE) or public insurance (Medicare, Medicaid, Veteran's Administration, and Children's Health Insurance Program, which is KidCare in Florida). Infants with mixed payer status had multiple payers for hospitalizations in the first year of life.

Hospital Charges and Estimated Costs

All dollar values are reported as 2011 U.S. dollars calculated using the Purchaser Price Index for hospitals (U.S. Bureau of Labor Statistics, 2012). AHCA reports inpatient facility charges, excluding professional fees. Based on state-level hospital data from the Agency for Healthcare Research and Quality's State Inpatient Database, the average all-payer inpatient hospital cost-to-charge ratio among Florida hospitals for 2009 (n =217 hospital reporting) was 0.281, suggesting hospitals' costs average approximately 28% of the amount those hospitals bill to healthcare payers (AHRQ, 2012). We converted patient charges to estimated costs using this statewide cost-to-charge ratio. Our analysis focused on relative comparisons of inpatient experiences for infants with timely and late detected CCHD; we did not attempt to estimate the total financial burden attributable to CCHD during infancy. We did not attempt to estimate the total financial burden attributable to CCHD during infancy.

Mortality Classification During Infancy

Mortality among infants with late detected CCHD was classified as: (1) *Nonhospital death without hospital readmission* =infant died following birth hospitalization without any subsequent hospital readmissions; (2) *Death upon emergent readmission after birth hospitalization* =infant died within 3 days of an "emergency" or "urgent" inpatient admission following birth hospitalization; and (3) *Other death during infancy* =all other deaths among infants with late detected CCHD during the first year of life. Deaths under the

first two circumstances might be avoidable through timely CCHD detection with screening done at the birth hospital. Based on available data, we were not able to further investigate additional circumstances in which mortality might be avoided. In multivariable analyses described below, we controlled for mortality when assessing the relative financial impact of late CCHD detection.

Statistical Analysis

We assessed inpatient hospital resource use for the newborn and infant periods in terms of number of admissions, hospitalized days, and estimated costs. We report mean and median estimates for each measure of hospital use. Because hospital resource use indicators were right-skewed (meaning, a low number of infants had a high number of hospital admissions, number of hospitalized days, and estimated inpatient costs), the mean exceeds the median for each measure. Mean cost is used in economic analyses because total cost is the product of mean cost per case and the number of cases. Median costs might be useful, for example, to project the expected healthcare use of an individual infant. Mean cost measures are relevant for population-level analyses and are the primary focus of this study.

We compared mean hospital resource use between newborns and infants with timely versus late detected CCHD using sum rank tests. Because factors related to timely CCHD detection could drive observed mean group differences (e.g., timely detected CCHD could be more severe, leading to greater resource use), we used linear regression models to examine associations between late CCHD detection and hospital resource use that controlled for selected maternal/household and infant characteristics. Maternal/household characteristics included: maternal age, race/ethnicity, nativity, education, and expected principal healthcare payer status during the infant's first year of life. Infant characteristics included: sex, preterm birth, noncardiac congenital anomalies, death during infancy, birth hospitalization nursery care level, and type of CCHD. The continuous measures of hospital resource use indicators (i.e., number of hospitalized days) were log-transformed for the analysis. Because of the transformation, model results are reported as exp(β) and interpreted as percentage changes in the dependent variables associated with unit changes in the (non–log-transformed) independent variables (Vittinghoff et al., 2012). All models controlled for infants' birth year.

RESULTS

During 1998 to 2007, 2,135,079 live births occurred in Florida, of which 2,128,236 (99.7%) occurred in hospitals (FDOH, 2013). The FBDR identified 4105 infants with relevant ICD-9-CM codes for CCHD during that period, of which 3655 (89%) had an associated birth hospitalization discharge record. Among those infants, 3603 (99%) had an inpatient CCHD diagnosis or a record of death due to any cause within the first year of life and were included in this analysis (Table 1). Just under 43% (n =1547) of infants were transferred to another hospital during the birth hospitalization (data not shown).

Late Detection and Death During Infancy

Approximately 23% (n =825/3603) of infants had late detected CCHD, meaning no CCHD diagnosis code appeared on the birth hospitalization discharge record (Table 2). Among

infants with one of the seven CCHD conditions considered a primary target of newborn screening, 21% (*n* =348/1639) were late detected. The median age of detection in an inpatient setting among infants with late detected CCHD was 88 days (range: 2–364). Overall, 18% of infants with CCHD died during infancy (Table 3). Among infants with timely detected CCHD, 20% (*n* =568/2778) died during infancy, compared with 8% (*n* =66/825) of infants with late detected CCHD, unadjusted for clinical characteristics. Among infants with late detected CCHD, 0.8% (*n* =7/825) died outside of a hospital following the birth hospitalization without readmission and 1% (*n* =8/825) died upon emergent hospital readmission. This equates to an estimated potentially avoidable mortality of 0.4% (*n* =15/3603) among all infants with CCHD once universal screening is implemented.

Late Detection and Hospital Resource Usage

Based on a simple comparison of means, during the neonatal period newborns with late detected CCHD had significantly more hospital admissions compared with infants with timely detected CCHD (1.3 vs. 1.0 admissions, respectively) (Table 4), although newborns with late detected CCHD had significantly fewer hospitalized days for admissions initiated during the neonatal period (15.3 vs. 27.3 days, respectively) (Table 4) and lower estimated inpatient costs (approximately $31,300 vs. $72,000, respectively) (Table 5). This pattern was consistent when hospitalizations initiated any time during infancy were analyzed. Infants with late detected CCHD had significantly more hospital admissions during the entire first year of life compared with infants with timely detected CCHD (3.0 vs. 2.1 admissions, respectively) (Table 4), although fewer hospitalized days (30.1 vs. 37.5 days, respectively) (Table 4), and lower estimated inpatient costs (approximately $69,500 vs. $100,200, respectively) (Table 5).

The overall picture of greater inpatient resource use among infants with timely detected CCHD changed in the multivariable analysis that assessed all of infancy. First, during the newborn period and controlling for selected characteristics, late CCHD detection was significantly associated with 16% more hospital admissions during the newborn period but 38% fewer hospitalized days and 63% lower estimated inpatient costs (Table 6). However, for all of infancy, late CCHD detection was associated with 52% more admissions, 18% more hospitalized days, and 35% higher inpatient costs during infancy. Relative to hypoplastic left heart syndrome, only multiple CCHD was associated with higher estimated inpatient costs during infancy. Preterm birth and the presence of a noncardiac congenital anomaly were associated with 12% and 45% higher estimated inpatient costs during infancy, respectively. Infant death was associated with 22% lower estimated inpatient costs during infancy. Compared with Level III nursery care, Level I or II care during the birth hospitalization were each associated with over 60% lower estimated inpatient costs during infancy. Younger maternal age (<25 years old) was significantly associated with lower estimated inpatient costs during infancy relative to mothers 25 to 34 years old. Non-Hispanic black and Hispanic mothers of children with CCHD had higher inpatient costs during infancy compared with non-Hispanic white mothers. Relative to infants with private hospital payer sources, infants with public or mixed payer sources had significantly higher estimated inpatient costs and infants with no insurance had significantly lower estimated inpatient costs (Table 5).

DISCUSSION

This analysis estimated that 23% of infants with CCHD were diagnosed after birth hospital discharge, suggesting that many infants might benefit from universal screening. A basic comparison of mean resource use initially suggested that infants with late detected CCHD had lower inpatient resource use, although once we adjusted for factors that contributed jointly to late detection and hospital resource use (such as death, CCHD type, preterm birth, and hospital level), late CCHD detection was associated with 52% more admissions, 18% more hospitalized days, and 35% higher estimated inpatient costs during infancy. Our study provides indirect evidence that cost-savings in inpatient care during infancy might occur if more infants with CCHD are detected at birth hospitals through CCHD screening. Our results also suggested significant differences in hospital resource use among newborns and infants with CCHD based on preterm birth, maternal age, race, and health-care payer.

Infants with late detected CCHD in this study had a lower unadjusted mortality rate than infants with timely detected CCHD (8% vs. 20%). This observed difference in mortality is likely due to more severe conditions present among infants with timely detected CCHD. This finding is consistent with a recent population-based study using birth defects registry data from the Metropolitan Atlanta Congenital Defects Program that estimated better survival for infants with CCHD diagnosed after their day of birth (Oster et al., 2013). We reported 1.8% of infants with late-detected CCHD (and 0.4% of all infants with CCHD) experienced deaths in emergency settings (at home or soon after an emergent readmission) that might have been avoided if they had received a diagnosis during the birth hospitalization. Infants that die during the first year of life might have lower inpatient resource use, therefore, we controlled for mortality in the multivariable analyses. We conducted an additional test of our resource estimates by restricting the analysis to infants that survived the first year; these results were substantively unchanged compared with the results using the full dataset.

A limitation of this study was its reliance on a passive state birth defects registry, which did not include clinically verified diagnoses (Frohnert et al., 2005; Strickland et al., 2008). The FBDR is reported to miss up to 15% of birth defects, depending on the defect (Salemi et al., 2011) and, thus, may have incomplete ascertainment of CCHD. Incomplete ascertainment and imprecise reporting of diagnoses would be a problem for this analysis primarily if such omissions and errors were systematically linked to the timing of CCHD detection, which may be unlikely. Our analysis relied on hospital-based information from one state, which may limit generalizability. The lack of outpatient costs included in this analysis is a limitation in our assessment of resource use. Some infants' post-birth hospital visits may have occurred outside Florida and were not included in our analysis. Another limitation is that we excluded 502 (12.2%) infants with CCHD identified by the FBDR who had no matching hospital records; those infants were significantly more likely to have been born to mothers who were foreign-born, unmarried, less educated, and of Hispanic ethnicity and were also more likely to be multiple births (data not shown). We did not examine infants that were live-born in hospital but died before hospital admission (Tanner et al., 2010), although it is unlikely that such infants would be able to benefit from CCHD screening. Another limitation is that the FBDR does not include linked maternal labor and delivery

records; some hospital costs related to newborn care might have been applied to mothers' records.

These limitations are balanced by several strengths. Although this analysis applies to just one state, Florida has the fourth-largest number of births in the United States (Hamilton et al., 2010). All facilities in the state performing surgical procedures for congenital heart defects were included. Linkage with vital records allowed us to quantify the number of deaths that might be avoided in the context in which screening is now recommended to occur in the United States. We examined patient characteristics not previously studied in this context. Importantly, we used data that allowed us to examine the health and financial outcomes for infants with timely versus late detected CCHD over the infants' entire first year of life. This study illustrates the usefulness of population-based birth defects surveillance data in combination with other administrative data sets (Olney and Botto, 2012). Other states with birth defects registries could conceivably replicate this approach.

This study compared inpatient resource use among infants with timely versus late detected CCHD in Florida and concluded that inpatient costs might be reduced if more newborns with CCHD are detected at birth hospitals through universal screening. This study supports recent evidence that infant deaths would likely be avoided through universal screening. Additional population-based studies using active birth defects registry data with clinically verified CCHD conditions and conducted after screening implementation are needed to confirm these findings.

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Table 1

Selected Characteristics of Florida Live-Born Infants with Critical Congenital Heart Disease (CCHD) (n = 3603), 1998 to 2007

Characteristic	Infants, *n* (%)
Mother / household	
Mother's age, years	
≤24	1266 (35.1)
25–34	1714 (47.7)
≥35	623 (17.3)
Mother's race/ethnicity	
White, non-Hispanic	1966 (54.6)
Black, non-Hispanic	799 (22.2)
Hispanic	741 (20.6)
Asian/Pacific Islander and American Indian/Alaskan	67 (1.9)
Other or unknown	30 (0.8)
Mothers nativity: foreign-born	840 (23.3)
Mother's education	
Less than high school graduate	741 (20.6)
High school graduate or equivalent	1216 (33.8)
At least some college or university	1615 (44.8)
Unknown	31 (0.9)
Principal healthcare payer during first year of life[a]	
Private	1510 (41.9)
Public	1602 (44.5)
Self/underinsured/charity	39 (1.1)
Mixed	452 (12.6)
Infant	
Sex, female	1556 (43.2)
Preterm or very preterm birth (20–36 weeks)	738 (20.5)
Non–cardiac congenital anomaly	1133 (31.5)
Death during infancy	634 (17.6)
Birth hospital nursery care level[b]	
I	305 (8.5)
II	395(11.0)
III	2903 (80.6)
Critical congenital heart disease type	
Single CCHD	
Aortic interruption / atresia / hypoplasia	96 (2.7)
Coarctation/hypoplasia of aortic arch	747 (20.7)
Double-outlet right ventricle	109 (3.0)
Dextro-transposition of the great arteries[c]	260 (7.2)
Ebstein anomaly	87 (2.4)

Characteristic	Infants, *n* (%)
Hypoplastic left heart syndrome[c]	223 (6.2)
Pulmonary atresia[c]	96 (2.7)
Single ventricle	32 (0.9)
Truncus arteriosus[c]	101 (2.8)
Total anomalous pulmonary venous connection[c]	92 (2.6)
Tetralogy of Fallot[c]	745 (20.7)
Tricuspid atresia[c]	122 (3.4)
Multiple CCHD	893 (24.8)

[a] Private insurance included employer-based insurance (including TRICARE). Public insurance included Medicare, Medicaid, Veteran's Administration, and other state and local government insurance in Florida (e.g., Children's Health Insurance Program, KidCare). Mixed payer status meant that an infant had multiple healthcare payers for hospitalizations in the first year of life.

[b] If a transfer occurred during the birth hospitalization, nursery level was coded as the highest facility level experienced.

[c] Conditions identified as primary targets for pulse oximetry screening (Mahle et al., 2009; Kemper et al., 2011).

Table 2

Timely versus Late Detection of Critical Congenital Heart Disease (CCHD) among Florida Live-Born Infants (*n* =3603), 1998 to 2007

		Late detected	
CCHD condition	**Timely detected[a] *n* (%)**	***n* (%)**	**Median age (range) at detection, days[b]**
All (*n*=3603)	2778 (77.1)	825 (22.9)	88 (2–364)
Single CCHD			
AI/A (*n*=96)	70 (72.9)	26 (27.1)	71 (4–364)
COA (*n*=747)	472 (63.2)	275 (36.8)	41 (2–347)
DORV (*n*=109)	77 (70.6)	32 (29.4)	90 (6–327)
d-TGA (*n*=260)[c]	234 (90.0)	26 (10.0)	46 (6–122)
EA (*n*=87)	76 (87.4)	11 (12.6)	56 (15–216)
HLHS (*n*=223)[c]	196 (87.9)	27 (12.1)	18 (3–280)
PA (*n*=96)[c]	74 (77.1)	22 (22.9)	47 (8–228)
SV (*n*=32)	24 (75.0)	8 (25.0)	140 (40–264)
TA (*n*=101)[c]	69 (68.3)	32 (31.7)	46 (10–229)
TAPVC (*n*=92)[c]	55 (59.8)	37 (40.2)	62 (3–289)
TOF (*n*=745)[c]	561 (75.3)	184 (24.7)	108 (2–358)
TRA (*n*=122)[c]	102 (83.6)	20 (14.0)	162 (11–235)
Multiple CCHD (*n*=893)	768 (86.0)	125 (14.0)	51 (2–356)

[a] Timely detection at the birth hospital =Any ICD-9-CM code for CCHD noted on inpatient birth hospital discharge record.

[b] Age in days assessed as the day of first hospital admission on which a congenital heart disease ICD-9-CM code appeared in the discharge record.

[c] Conditions identified as primary targets for pulse oximetry screening (Mahle et al., 2009; Kemper et al., 2011).

AI/A, aortic interruption/atresia / hypoplasia; COA, coarctation / hypoplasia of aortic arch; DORV, double-outlet right ventricle; d-TGA dextro-transposition of the great arteries; EA Ebstein anomaly; HLHS hypoplastic left heart syndrome; PA pulmonary atresia; SV single ventricle; TA truncus arteriosus; TAPVC total anomalous pulmonary venous connection; TOF tetralogy of Fallot;TRA tricuspid atresia.

Table 3

Mortality among Florida Live-Born Infants with Critical Congenital Heart Disease (CCHD) (*n* =3603), 1998 to 2007

	Deaths during infancy	
	n	**%**
All (*n*= 3603)	634	17.6
Infants with timely detected[a] CCHD (*n*= 2778)	568	20.4
Infants with late detected CCHD (*n*= 825)	66	8.0
Infant deaths in a non-hospital setting without hospital readmission	7	0.8
Infants deaths within three days of an emergent readmission	8	1.0
Deaths at another time during infancy	51	6.2

[a]Timely detection at the birth hospital =Any ICD-9-CM code for CCHD noted on inpatient birth hospital discharge record.

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Table 4

Description of Number of Hospital Admissions and Hospitalized Days among Florida Live-Born Infants with Critical Congenital Heart Disease (CCHD) (*n* =3603), 1998 to 2007

	Timely detection				Late detection			
	Hospital admissions[a] (*n*)		Hospitalized days[a]		Hospital admissions[a] (*n*)		Hospitalized days[a]	
CCHD condition	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)
	Hospitalizations[b] initiated during neonatal period: <28 days old							
All (*n*=3603)	1.0 (0.2)	1.0 (0.0)	27.3 (34.3)	17.0 (28.0)	1.3 (0.5)[c]	1.0 (1.0)[c]	15.3 (26.3)[c]	4.0 (14.0)[c]
Single CCHD								
AI/A (*n*=96)	1.0 (0.2)	1.0 (0.0)	26.3 (35.0)	19.5 (34.0)	1.2 (0.4)[c]	1.0 (0.0)[c]	12.7 (29.6)[c]	3.0 (7.0)[c]
COA (*n*=747)	1.0 (0.2)	1.0 (0.0)	26.4 (32.2)	15.0 (27.0)	1.4 (0.5)[c]	1.0 (1.0)[c]	10.5 (16.8)[c]	4.0 (10.0)[c]
DORV (*n*=109)	1.0 (0.2)	1.0 (0.0)	24.7 (29.7)	12.0 (33.0)	1.1 (0.3)	1.0 (0.0)	14.0 (21.0)[c]	4.0 (13.0)[c]
d-TGA (*n*=260)[d]	1.0 (0.2)	1.0 (0.0)	23.3 (24.6)	19.0 (15.0)	1.3 (0.5)[c]	1.0 (1.0)[c]	14.8 (20.7)[c]	6.5 (17.0)[c]
EA (*n*=87)	1.0 (0.2)	1.0 (0.0)	17.3 (28.8)	6.5 (17.0)	1.4 (0.5)[c]	1.0 (1.0)[c]	17.9 (18.6)	9.0 (36.0)
HLHS (*n*=223)[d]	1.0 (0.1)	1.0 (0.0)	38.9 (48.2)	21.0 (54.0)	1.5 (0.5)[c]	1.0 (1.0)[c]	25.2 (35.0)	18.0 (29.0)
PA (*n*=96)[d]	1.1 (0.2)	1.0 (0.0)	25.0 (26.4)	17.0 (22.0)	1.2 (0.4)	1.0 (0.0)	24.2 (34.4)	10.0 (30.0)
SV (*n*=32)	1.1 (0.3)	1.0 (0.0)	26.7 (38.6)	15.0 (25.5)	1.0 (0.0)	1.0 (0.0)	26.4 (32.2)	14.0 (36.5)
TA (*n*=101)[d]	1.1 (0.2)	1.0 (0.0)	25.7 (25.2)	22.0 (25.0)	1.2 (0.4) [c]	1.0 (0.0)[c]	21.6 (36.1)[c]	8.5 (18.5)[c]
TAPVC (*n*=92)[d]	1.1 (0.2)	1.0 (0.0)	25.5 (18.0)	23.0 (21.0)	1.4 (0.5)[c]	1.0 (1.0)[c]	7.8 (10.1)[c]	3.0 (9.0)[c]
TOF (*n*=745)[d]	1.1 (0.2)	1.0 (0.0)	20.9 (33.9)	7.0 (20.0)	1.2 (0.4)[c]	1.0 (0.0)[c]	14.3 (27.6)[c]	3.0 (7.0)[c]
TRA (*n*=122)[d]	1.0 (0.2)	1.0 (0.0)	19.7 (29.6)	9.5 (17.0)	1.1 (0.3)	1.0 (0.0)	18.7 (30.7)	5.0 (27.5)
Multiple CCHD (*n*=893)	1.0 (0.2)	1.0 (0.0)	33.7 (36.0)	22.0 (32.0)	1.4 (0.6)[c]	1.0 (1.0)[c]	23.7 (36.7)[c]	8.0 (30.0)[c]
	Hospitalizations[b] initiated during infancy: <365 days old							
All (*n*=3603)	2.1 (1.6)	1.0 (2.0)	37.5 (44.3)	23.0 (37.0)	3.0 (1.5)[c]	2.0 (2.0)[c]	30.1 (41.1)[c]	17.0 (24.0)[c]
Single CCHD								
AI/A (*n*=96)	1.6 (1.0)	1.0 (1.0)	30.6 (37.3)	21.5 (40.0)	3.1 (1.5)[c]	2.0 (1.0)[c]	36.3 (103.9)	9.0 (17.0)
COA (*n*=747)	1.8 (1.5)	1.0 (1.0)	32.0 (37.6)	17.0 (35.0)	2.9 (1.7)[c]	2.0 (1.0)[c]	21.7 (28.0) [c]	9.0 (15.0)[c]
DORV (*n*=109)	1.7 (1.0)	1.0 (1.0)	29.4 (32.8)	19.0 (37.0)	3.0 (1.2)[c]	2.0 (2.0)[c]	27.7 (26.8)	15.5 (36.5)

	Timely detection				Late detection			
	Hospital admissions[a] (*n*)		Hospitalized days[a]		Hospital admissions[a] (*n*)		Hospitalized days[a]	
CCHD condition	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)
D-TGA (*n*=260)[d]	1.6 (1.2)	1.0 (1.0)	25.7 (26.4)	21.0 (17.0)	2.7 (2.1)[c]	2.0 (1.0)[c]	27.0 (23.7)	19.5 (19.0)
EA (*n*=87)	1.5 (1.4)	1.0 (0.0)	24.2 (47.8)	6.5 (17.5)	2.5 (1.6)[c]	2.0 (1.0)[c]	26.7 (25.1)	18.0 (31.0)
HLHS (*n*=223)[d]	1.8 (1.4)	1.0 (1.0)	46.1 (53.6)	24.5 (66.0)	3.1 (1.5 [c]	2.0 (2.0)[c]	36.6 (42.9)	25.0 (35.0)
PA (*n*=96)[d]	1.6 (1.1)	1.0 (1.0)	30.3 (34.5)	19.5 (32.0)	3.0 (1.7)[c]	2.0 (2.0)[c]	38.8 (40.3)	31.0 (58.0)
SV (*n*=32)	1.6 (1.0)	1.0 (1.0)	29.4 (39.4)	19.0 (35.0)	3.6 (1.2)[c]	4.0 (2.0)[c]	49.5 (46.8)	36.5 (54.5)
TA (*n*=101)[d]	2.0 (1.4)	1.0 (1.0)	34.4 (43.9)	24.0 (24.0)	2.5 (1.3)[c]	2.0 (1.0)[c]	29.8 (34.9)	17.0 (22.5)
TAPVC (*n*=92)[d]	2.0 (1.5)	1.0 (1.0)	30.5 (20.7)	27.0 (28.0)	2.6 (1.2)[c]	2.0 (1.0)[c]	23.9 (26.1) [c]	17.0 (10.0)[c]
TOF (*n*=745)[d]	2.4 (1.5)	2.0 (2.0)	33.0 (45.2)	17.0 (30.0)	2.9 (1.3)[c]	2.0 (1.0)[c]	27.0 (36.0)	13.5 (20.0)
TRA (*n*=122)[d]	2.0 (1.4)	1.0 (2.0)	26.8 (36.8)	16.0 (26.0)	3.1 (1.7)[c]	2.0 (2.0)[c]	39.2 (42.3)	25.5 (35.0)
Multiple CCHD (*n*=893)	2.8 (1.8)	1.0 (3.0)	51.4 (49.7)	36.0 (46.5)	3.6 (1.9)[c]	2.0 (3.0)[c]	49.5 (53.4)	32.0 (41.0)

[a] Resource utilization indicators refer to admissions initiated, but not necessarily completed, within the specified period. “Hospitalized days” refers to the number of days that an infant spent in the hospital for all admissions initiated within the specified period.

[b] Hospitalizations were assessed as continuous episodes of hospital care, regardless of whether a transfer occurred. Multiple admission records were merged into one if an infant was admitted to a hospital on the same day as a discharge from a previous admission, or if the infant was admitted to a hospital on the day after a previous discharge with an accompanying “transfer” code. The level of birth hospitalization nursery care (I, III, or III [highest]) (American Academy of Pediatrics Committee on Fetus and Newborn, 2004) that an infant received was coded as the highest facility level if a transfer occurred.

[c] $p<0.05$ for test of timely versus late detection (Mann-Whitney-Wilcoxon rank sum test).

[d] Conditions identified as primary targets for pulse oximetry screening (Mahle et al., 2009; Kemper et al., 2011).

IQR, interquartile range; AI/A, aortic interruption/atresia/hypoplasia; COA, coarctation/hypoplasia of aortic arch; DORV, double-outlet right ventricle; d-TGA, dextro-transposition of the great arteries; EA, Ebstein anomaly; HLHS, hypoplastic left heart syndrome; PA, pulmonary atresia; SD, standard deviation; SV, single ventricle; TA, truncus arteriosus; TAPVC, total anomalous pulmonary venous connection; TOF, tetralogy of Fallot; TRA, tricuspid atresia.

Table 5

Estimated Inpatient Costs among Florida Live-Born Infants with Critical Congenital Heart Disease (CCHD) (*n* =3603), 1998 to 2007

	Timely detection		Late detection	
	Estimated inpatient costs[a] ($)		Estimated inpatient costs[a] ($)	
CCHD condition	**Mean (SD)**	**Median (IQR)**	**Mean (SD)**	**Median (IQR)**
	Hospitalizations[b] initiated during neonatal period: <28 days old			
All (*n*=3603)	72,001 (99,396)	40,918 (85,341)	31,270 (71,511)[c]	4,069 (30,574)[c]
Single CCHD				
AI/A (*n*=96)	70,831 (97,055)	50,261 (79,433)	34,719 (37,025)[c]	1,445 (10,787)[c]
COA (*n*=747)	60,255 (101,814)	30,198 (59,335)	19,727 (37,025)[c]	4,142 (21,930)[c]
DORV (*n*=109)	67,930 (93,274)	29,764 (97,888)	32,595 (72,547)[c]	2,506 (29,466)[c]
d-TGA (*n*=260)[d]	77,395 (68,130)	70,216 (44,381)	25,644 (30,455)[c]	11,958 (50,109)[c]
EA (*n*=87)	37,961 (82,201)	7,764 (46,721)	39,048 (71,024)	9,284 (36,593)
HLHS (*n*=223)[d]	120,592 (141,053)	78,778 (163,537)	51,034 (56,020)[c]	36,887 (80,209)[c]
PA (*n*=96)[d]	75,466 (90,202)	47,312 (95,093)	51,431 (112,822)	16,840 (49,947)
SV (*n*=32)	52,919 (73,127)	29,572 (70,526)	69,321 (110,635)	36,195 (71,927)
TA (*n*=101)[d]	68,672 (76,123)	51,385 (81,848)	38,905 (92,647)[c]	7,868 (39,236)[c]
TAPVC (*n*=92)[d]	79,990 (66,603)	64,800 (72,601)	26,653 (48,970)[c]	1,173 (46,572)[c]
TOF (*n*=745)[d]	39,094 (75,537)	8,152 (36,948)	20,347 (65,175)[c]	1,760 (9,224)[c]
TRA (*n*=122)[d]	43,277 (99,801)	12,458 (46,217)	28,588 (59,351)	3,644 (29,647)
Multiple CCHD (*n*=893)	96,900 (104,751)	72,628 (97,745)	61,763 (106,949)[c]	11,521 (89,308)[c]
	Hospitalizations[b] initiated during infancy: <365 days old			
All (*n*=3603)	100,150 (124,511)	67,727 (104,495)	69,486 (106,781)[c]	38,149 (60,545)[c]
Single CCHD				
AI/A (*n*=96)	78,724 (101,145)	61,946 (98,619)	96,164 (282,737)	31,176 (63,680)
COA (*n*=747)	72,213 (111,655)	36,452 (74,704)	46,917 (76,835)[c]	25,922 (34,264)[c]
DORV (*n*=109)	83,430 (105,109)	49,491 (118,201)	77,762 (87,433)	52,877 (54,121)
D-TGA (*n*=260)[d]	82,641 (69,402)	72,390 (46,223)	55,669 (38,166)	53,154 (72,719)
EA (*n*=87)	53,336 (114,959)	7,764 (50,199)	55,650 (71,197)	34,034 (73,467)
HLHS (*n*=223)[d]	142,500 (161,243)	93,598 (207,094)	74,962 (68,789)	56,338 (111,825)
PA (*n*=96)[d]	92,438 (115,600)	56,644 (115,141)	83,702 (122,233)	72,532 (87,352)
SV (*n*=32)	64,237 (75,736)	48,296 (90,986)	113,922 (112,081)	102,813 (64,586)
TA (*n*=101)[d]	95,820 (136,630)	65,500 (75,337)	60,140 (90,736)	37,424 (47,090)
TAPVC (*n*=92)[d]	90,460 (76,563)	65,891 (88,155)	63,281 (51,501)	47,702 (42,543)
TOF (*n*=745)[d]	74,226 (102,781)	42,295 (64,557)	53,945 (72,871)	33,492 (33,449)
TRA (*n*=122)[d]	61,028 (136,025)	30,726 (56,279)	89,627 (107,253)[c]	59,455 (52,711)[c]
Multiple CCHD (*n*=893)	147,189 (138,378)	110,709 (128,431)	132,917 (145,934)[c]	88,395 (118,595)[c]

[a] Presented as 2011 values (U.S. Bureau of Labor Statistics, 2012). Estimated costs calculated as total inpatient facility charges multiplied by the Florida average hospital cost-to-charge ratio (0.281 in 2009) (AHRQ, 2012). Inpatient charges include all hospital facility charges (excludes professional fees): Pharmacy, medical and surgical supply, laboratory, radiology and other imaging, cardiology, operating room, anesthesia, recovery room, emergency room (if an inpatient admission originated in the emergency room), treatment or observation room (if a visit resulted in an inpatient admission) charges (AHCA, 2012).

[b] Hospitalizations were assessed as continuous episodes of hospital care, regardless of whether a transfer occurred. Multiple admission records were merged into one if an infant was admitted to a hospital on the same day as a discharge from a previous admission, or if the infant was admitted to a hospital on the day after a previous discharge with an accompanying "transfer" code. The level of birth hospitalization nursery care (I, III, or III [highest])]) (American Academy of Pediatrics Committee on Fetus and Newborn, 2004) that an infant received was coded as the highest facility level if a transfer occurred.

[c] $p < 0.05$ for test of timely versus late detection (Mann-Whitney-Wilcoxon rank sum test).

[d] Conditions identified as primary targets for pulse oximetry screening (Mahle et al., 2009; Kemper et al., 2011).

IQR, Interquartile range; AI/A, aortic interruption/atresia/hypoplasia; COA, coarctation/hypoplasia of aortic arch; DORV, double-outlet right ventricle; d-TGA dextro-transposition of the great arteries; EA, Ebstein anomaly; HLHS, hypoplastic left heart syndrome; PA, pulmonary atresia; SV, single ventricle; TA, truncus arteriosus; TAPVC, total anomalous pulmonary venous connection; TOF, tetralogy of Fallot; TRA, tricuspid atresia.

Table 6

Factors Associated with Hospital Resource Utilization among Florida Live-Born Infants with Critical Congenital Heart Disease (CCHD) (*n*=3603), 1998 to 2007

	Hospital admissions		Hospitalized days		Estimated inpatient costs[a]	
	Neonatal period (<28 days)	Infancy (<365 days)	Neonatal period (<28 days)	Infancy (<365 days)	Neonatal period (<28 days)	Infancy (<365 days)
Characteristic	**exp(β) (95%CI)[b]**	**exp(β) (95%CI) [b]**	**exp(β) (95%CI)[b]**	**exp(β) (95%CI) [b]**	**exp(β) (95%CI) [b]**	**exp(β) (95%CI) [b]**
Mother/household						
Mother's age (ref: 25–34 years)						
≤24	1.01 (0.99–1.02)	1.00(0.96–1.04)	0.94(0.86–1.02)	0.94(0.86–1.02)	0.93(0.82–1.05)	**0.90(0.81–1.00)**
≥35	1.00 (0.99–1.00)	0.99(0.97–1.00)	0.99(0.96–1.02)	0.98(0.95–1.02)	0.98(0.93–1.03)	0.98(0.94–1.02)
Mother's race ethnicity (ref: white, non-Hispanic) [c]						
Black, non-Hispanic	1.00 (0.98–1.02)	1.03(0.99–1.08)	1.10(1.00–1.21)	**1.14(1.04–1.26)**	1.09(0.95–1.25)	**1.14(1.02–1.28)**
Hispanic	1.00 (0.98–1.02)	**1.08(1.03–1.14)**	1.01(0.90–1.13)	1.06(0.95–1.19)	1.09(0.93–1.28)	**1.19(1.03–1.36)**
Asian/Pacific Islander, American Indian/Alaskan	1.00 (0.95–1.05)	1.08(0.95–1.23)	0.99(0.75–1.31)	1.04(0.79–1.37)	0.88(0.60–1.29)	0.97(0.69–1.35)
Mother's education (ref: At least some college or university) [c]						
Less than high school graduate	0.99 (0.97–1.01)	1.02(0.97–1.07)	**1.13(1.01–1.26)**	1.09(0.97–1.21)	1.07(0.91–1.25)	0.98(0.86–1.12)
High school graduate	1.00 (0.98–1.01)	1.00(0.96–1.04)	1.04(0.95–1.14)	1.06(0.97–1.16)	1.01(0.89–1.14)	1.02 (0.92–1.13)
Mother's nativity: foreign-born	1.01 (0.99–1.03)	0.98(0.93–1.03)	1.01(0.91–1.12)	0.99(0.89–1.10)	1.05(0.91–1.22)	1.02(0.90–1.15)
Healthcare payer status (ref: private)						
Public	1.00(0.98–1.01)	**1.08(1.04–1.13)**	**1.24(1.13–1.36)**	**1.34(1.23–1.47)**	**1.21(1.07–1.38)**	**1.25(1.12–1.40)**
Self/uninsured/charity	0.96(0.90–1.02)	**0.73(0.62–0.86)**	**0.68(0.48–0.97)**	**0.43(0.30–0.61)**	**0.49(0.30–0.80)**	**0.29(0.19–0.45)**
Mix	1.01(0.98–1.03)	**1.30(1.23–1.38)**	**1.27(1.12–1.43)**	**1.60(1.42–1.80)**	**1.38(1.16–1.63)**	**1.73(1.50–2.01)**
Infant						
Sex, female	0.99(0.98–1.01)	0.99(0.95–1.02)	1.07(0.99–1.15)	1.04(0.96–1.11)	1.03(0.94–1.15)	0.99(0.91–1.08)
Preterm or very preterm birth	**0.97(0.96–0.99)**	0.98(0.94–1.02)	**1.45(1.32–1.59)**	**1.25(1.15–1.37)**	**1.41(1.25–1.61)**	**1.12(1.00–1.25)**
Non–cardiac congenital anomaly	1.00(0.99–1.02)	**1.24(1.20–1.29)**	**1.59(1.47–1.72)**	**1.60(1.48–1.73)**	**1.66(1.48–1.85)**	**1.45(1.32–1.60)**
Death during the period	1.00(0.97–1.02)	**0.61(0.58–0.64)**	**0.22(0.19–0.25)**	**0.50(0.46–0.56)**	**0.43(0.36–0.52)**	**0.78(0.69–0.88)**
Birth hospital nursery care level (ref: III)						
I	**1.13(1.10–1.15)**	**0.92(0.86–0.99)**	**0.41(0.36–0.48)**	**0.50(0.44–0.58)**	**0.23(0.19–0.28)**	**0.38(0.32–0.45)**

	Hospital admissions		Hospitalized days		Estimated inpatient costs[a]	
	Neonatal period (<28 days)	Infancy (<365 days)	Neonatal period (<28 days)	Infancy (<365 days)	Neonatal period (<28 days)	Infancy (<365 days)
Characteristic	**exp(β) (95%CI)[b]**	**exp(β) (95%CI) [b]**	**exp(β) (95%CI)[b]**	**exp(β) (95%CI) [b]**	**exp(β) (95%CI) [b]**	**exp(β) (95%CI) [b]**
II	**1.05(1.03–1.08)**	0.96(0.91–1.02)	**0.37(0.33–0.42)**	**0.49(0.43–0.55)**	**0.22(0.19–0.27)**	**0.40(0.35–0.47)**
CCHD type (ref: HLHS)						
Single CCHD						
AI/A	0.98(0.94–1.03)	**0.81(0.72–0.91)**	**0.59(0.46–0.77)**	**0.70(0.54–0.91)**	**0.46(0.32–0.67)**	**0.65(0.47–0.89)**
COA	1.02(0.99–1.06)	**0.81(0.75–0.87)**	**0.63(0.53–0.75)**	**0.71(0.60–0.84)**	**0.49(0.38–0.62)**	**0.62(0.51–0.76)**
DORV	0.97(0.93–1.02)	0.93(0.83–1.05)	**0.63(0.49–0.81)**	0.80(0.63–1.03)	**0.52(0.37–0.75)**	0.87(0.64–1.18)
d-TGA[d]	1.00(0.97–1.04)	**0.72(0.66–0.79)**	**0.78(0.64–0.95)**	**0.81(0.66–0.99)**	1.10(0.84–1.46)	1.19(0.93–1.52)
EA	0.99(0.94–1.04)	**0.75(0.66–0.85)**	**0.54(0.41–0.71)**	**0.53(0.40–0.69)**	**0.33(0.23–0.48)**	**0.31(0.23–0.44)**
PA[d]	1.00(0.95–1.05)	**0.82(0.72–0.92)**	0.77(0.59–1.01)	0.79(0.60–1.02)	0.80(0.55–1.15)	0.77(0.56–1.06)
SV	0.98(0.91–1.06)	0.93(0.77–1.13)	**0.61(0.40–0.92)**	0.80(0.53–1.19)	**0.46(0.26–0.82)**	0.68(0.42–1.11)
TA[d]	1.00(0.95–1.04)	**0.85(0.75–0.96)**	**0.71(0.55–0.92)**	0.83(0.64–1.07)	**0.60(0.42–0.86)**	0.80(0.58–1.10)
TAPVC[d]	1.01(0.97–1.06)	**0.84(0.74–0.95)**	**0.77(0.59–1.01)**	0.99(0.76–1.29)	0.86(0.59–1.25)	1.33(0.96–1.85)
TOF[d]	0.98(0.95–1.01)	1.01 (0.93–1.09)	**0.45(0.38–0.53)**	**0.77(0.65–0.91)**	**0.26(0.21–0.33)**	**0.76(0.62–0.93)**
TRA[d]	0.96(0.92–1.00)	0.90(0.80–1.01)	**0.55(0.43–0.70)**	**0.74(0.58–0.95)**	**0.33(0.24–0.47)**	**0.53(0.40–0.72)**
Multiple CCHD	1.01(0.98–1.04)	**1.20(1.11–1.29)**	0.95(0.80–1.11)	1.44(1.23–1.70)	1.05(0.84–1.32)	**1.88(1.54–2.29)**
Late CCHD detection	**1.16(1.14–1.18)**	**1.52(1.46–1.59)**	**0.62(0.56–0.68)**	**1.18(1.07–1.30)**	**0.37(0.32–0.43)**	**1.35(1.20–1.51)**

All models controlled for all variables listed in the table, as well as year of birth.

[a] Estimated costs calculated as total inpatient facility charges multiplied by the Florida average hospital cost-to-charge ratio (0.281 in 2009) (AHRQ, 2012).

[b] Due to the log-transformed dependent variables, regression results are presented as exp(β) and interpreted as percentage, rather than unit, changes in the dependent variable.

[c] Categories of “other” and missing values are not reported here.

[d] Conditions identified as primary targets for pulse oximetry screening (Mahle et al., 2009; Kemper et al., 2011).

Ref., referent group; AI/A, aortic interruption/atresia / hypoplasia; COA, coarctation/hypoplasia of aortic arch; DORV, double-outlet right ventricle; d-TGA, dextro-transposition of the great arteries; EA, Ebstein anomaly; HLHS, hypoplastic left heart syndrome; PA, pulmonary atresia; SV, single ventricle; TA, truncus arteriosus; TAPVC, total anomalous pulmonary venous connection; TOF, tetralogy of Fallot; TRA, tricuspid atresia.