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Outcomes in Adult Congenital Heart Surgery: Analysis of the Society of Thoracic Surgeons (STS) Database

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Abstract

Objective(s)—Outcomes data for adults undergoing congenital heart surgery are limited. Previous analyses utilized administrative data or focused on single-center outcomes. We describe the most common operations, patient characteristics, and post-operative outcomes using a multicenter clinical database.

Methods—Adults (\geq 18 years) in the Society of Thoracic Surgeons (STS) Congenital Heart Surgery Database ((2000–2009) were included. Patient characteristics and morbidity and mortality were described. We similarly examined congenital procedures in the STS Adult Cardiac Surgery Database to permit consideration of the primary dataset within a broader context.

Results—5265 patients (68 centers) from the STS Congenital Heart Surgery Database were included. Median age was 25 years (IQR 20–35). Common preoperative risk factors included noncardiac abnormalities (17%) and arrhythmia (14%). Overall, in-hospital mortality was 2.1%, 27% had \geq 1 complication and median length of stay was 5 days. Common operations included right ventricular outflow tract procedures (21%) and pacemaker/arrhythmia procedures (20%). We further evaluated cardiopulmonary bypass procedures with n >100. Mortality ranged from 0% (atrial septal defect repair) to 11% (Fontan revision/conversion). Separate evaluation of the STS Adult Cardiac Surgery Database revealed 39,872 adults undergoing congenital heart operations.

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Conclusion—Most adult congenital heart operations in the STS Congenital Heart Surgery Database are performed in the third-fourth decades of life; nearly half are for right heart pathology or arrhythmia. Many patients have complications but mortality is low with the exception of those undergoing Fontan revision/conversion. Many more adults undergoing congenital heart surgery are entered into the STS Adult Cardiac Surgery Database.

INTRODUCTION

Recent estimates put the U.S. population of adults with congenital heart disease (ACHD) somewhere between one and three million.¹ Onlyrecently have these estimates exceeded those of pediatric patients with congenital heart disease. $^{2-4}$ There are many reasons for emergence of this population. As surgical techniques have improved, survival after even the most complex operations has dramatically improved over the past two decades.⁵ Advancements in supportive disciplines, including intensive care, have coincided with these operative improvements.^{2,6} Although most infants and children who undergo operations for congenital heart disease survive, the surgery rarely offers a definitive cure. With the exception of atrial septal defect (ASD) repair, the life expectancy of those born with congenital heart disease is lower than the general population.⁷ For many congenital cardiac lesions, the generation of patients currently reaching adulthood represents the first sizeable group to have done so and the late problems associated with surgically treated congenital heart disease are becoming increasingly apparent. Reports published to date have generally focused on individual lesions or on one aspect of caring for those with ACHD, and the majority report single institution experiences.^{8–10} Of multi-institutional reports, many rely on administrative data.¹¹

There is a paucity of reliable data available for use in counseling patients, families, and other clinicians with respect to mortality and expected complications for those with ACHD undergoing cardiac surgery. The Society of Thoracic Surgeons (STS) Congenital Heart Surgery Database collects perioperative information on all patients at participating institutions undergoing operations for congenital heart disease. Approximately three quarters of all centers performing congenital heart surgery submit data to this database, and therefore it is a potentially valuable repository of surgical information on ACHD patients.¹²

The primary objective of this study was to describe the patient characteristics, most common operations, and operative morbidity and mortality of patients ≥18 years of age undergoing surgery for congenital heart disease, utilizing the STS Congenital Heart Surgery Database. Information concerning patients undergoing surgery for congenital heart disease that is collected in the STS Adult Cardiac Surgery Database is considerably less detailed than that collected in the STS Congenital Heart Surgery Database. Nonetheless, we also sought to determine the overall number of ACHD operations that have been entered in the adult database during the same period of time in order to permit consideration of the primary dataset within a broader context.

MATERIALS AND METHODS

Data Source

The STS Congenital Heart Surgery Database contains operative, perioperative, and outcomes data on >180,000 patients undergoing congenital heart surgery since 1998. Data on all patients undergoing congenital heart surgery at participating centers are entered into the database. Data quality and reliability are assured through intrinsic verification of data and a formal process of site visits and data audits.¹³

In addition, we identified congenital procedures entered into the STS Adult Cardiac Surgery Database. While the adult database currently captures much more limited data regarding congenital heart operations, this information provides an estimate of the number of ACHD operations performed at adult hospitals or by adult cardiac surgeons.

The Duke Clinical Research Institute serves as the data warehouse and analytic center for all of the STS National Databases. This analysis was approved by the Duke institutional review board, and by the STS Access and Publications Committee.

Patient Population

Analysis of data from the STS Congenital Heart Surgery Database was restricted to 68 centers with >85% complete data for all study variables. While the STS Database contains nearly complete data for the standard core data fields required to calculate in-hospital mortality, not all centers submit complete data for all variables such as patient pre-operative characteristics or post-operative complications. Therefore, it is standard practice to exclude centers with >15% missing data for key study variables in order to maximize data integrity and minimize missing data.¹⁴ From the included centers, patients ≥18 years of age who underwent any congenital heart operation from 2000–2009 were included.

Similar criteria were applied to the STS Adult Cardiac Surgery Database. The only congenital operations captured in the adult database during this time period included ASD repair, pulmonary valve replacement, and "congenital defect repair".

Data Collection

Data collected from the STS Congenital Heart Surgery Database included demographic information, cardiac diagnoses, presence of non-cardiac/genetic abnormality, and the presence of any other preoperative factors as defined in the database including mechanical circulatory support, acidosis, shock, arrhythmia, atrioventricular block, pulmonary hypertension, mechanical ventilatory support, tracheostomy, renal failure (creatinine >2), renal failure requiring dialysis, bleeding disorder, endocarditis, sepsis, neurologic deficit, or seizure.¹⁵ Operative data included the surgical procedure performed which was analyzed individually and also categorized using the Society of Thoracic Surgeons- European Association for Cardiothoracic Surgery (STS-EACTS) risk stratification system (category 1 = lowest mortality risk, category 5 = highest mortality risk).¹⁶ This system was recently developed based on empiric data from nearly 80,000 patients, and it includes a greater number of operations compared with other risk stratification systems.¹⁶ The number of prior cardiothoracic operations was also collected, as well as cardiopulmonary bypass times. Outcomes data included in-hospital mortality, total postoperative length of stay, and postoperative complications including cardiovascular, pulmonary, neurologic, renal, infectious, and hematologic complications, as well as the need for unplanned surgical re-intervention during the hospitalization, as defined in the STS Database.¹⁵

Data collection from the STS Adult Cardiac Surgery Database was limited to the procedure performed (as captured in this database), demographics, and in-hospital mortality. Procedures in the adult database were categorized either as isolated procedures or as concomitant procedures in association with coronary artery bypass grafting, aortic valve procedure, and/or mitral valve procedure.

Analysis

Study variables were described using standard summary statistics. Pre-operative, operative, and outcomes data were described for the overall cohort as well as for subgroups of patients undergoing the most common operations. Due to the descriptive nature of the analysis,

formal statistical comparisons were not made. All analyses were performed using SAS version 9.2 (SAS Institute Inc, Cary, NC).

RESULTS

STS CONGENITAL HEART SURGERY DATABASE

Patient Characteristics and Overall Outcomes—A total of 5265 patients from 68 centers submitting data to the STS Congenital Heart Surgery Database were included in the primary analysis. Patient characteristics are displayed in Table 1. Overall, median age was 25 years [interquartile range (IQR) 20-35 years]. The most common preoperative risk factors were the presence of any non-cardiac/genetic abnormality (17%), and preoperative arrhythmia (14%). The most common categories of operations were right ventricular outflow tract/pulmonary artery procedure (21% of all operations; including pulmonary valve replacement or repair, conduit operation, and pulmonary artery reconstruction), pacemaker/ arrhythmia procedure (20%; including pacemaker or defibrillator implantation/procedure, and atrial or ventricular arrhythmia surgery), left ventricular outflow tract/aortic valve procedure (18%; including subaortic stenosis repair, aortic valve replacement or repair, aortic root replacement of any type, aortic aneurysm repair, Ross procedure and Ross-Konno procedure), ASD closure (7%), mitral valve repair or replacement (5%), and Fontan operation (4%; any type). In-hospital mortality for the overall cohort was 2.1%, 27% had one or more post-operative complications, and median post-operative length of stay was 5 days (IQR 3-7 days).

Patient characteristics & Outcomes Associated with the Most Common ACHD **Operations**—All individual operations involving cardiopulmonary bypass with n>100 were evaluated further; this included pulmonary valve replacement, ASD repair, right ventricle to pulmonary artery conduit operation, aortic aneurysm repair, mitral valvuloplasty, Ross operation, and Fontan revision/conversion. Tables 1-3 list the population characteristics, operative characteristics, and outcomes for these 7 operations. Pulmonary valve replacement was the most common operation. In-hospital mortality for this operation was low (0.7%) and median length of stay was 5 days (IQR 4-6 days). ASD patients were relatively old at the time of operation compared with the other operations (median 33 years, IQR 23-46). As expected, they had a short CPB time (median 61 minutes, IQR 43–87). ASD patients had a mortality of 0% and a short length of stay (median 4 days, IQR 3-5). The conduit operation cohort was notable for having a rate of preoperative neurologic deficit of 4.0%. Additionally, this group had a high number of previous cardiothoracic operations (median 2, IQR 1-3). The conduit operation cohort also had a relatively high rate of postoperative pulmonary complications (pleural effusion, reintubation, and mechanical ventilation > 7 days). The aortic aneurysm repair subgroup was notable for having a high rate of noncardiac/genetic abnormality (24% v. 17% overall) and the highest risk of postoperative heart block requiring a permanent pacemaker (2.2% v.1.3% overall). The patients undergoing mitral valvuloplasty were predominately female (72%) and had a high rate of noncardiac/genetic abnormality (27% v. 17% overall). These patients also had a high risk of postoperative arrhythmia (16% v 9.4% overall) and had a high rate of postoperative pleural effusion (8.2% v 3.1% overall). The Ross operation subgroup was relatively young (median 22 years, IQR 19-28) and had a low rate of noncardiac/genetic abnormality (6.5% v. 17% overall) and other preoperative risk factors (14% v. 31% overall). The Ross patients also had a long CPB time and a high rate of bleeding requiring reoperation (8.3% v. 1.9% overall). The Fontan revision/conversion cohort was notable for a high rate of any preoperative risk factor, long cardiopulmonary bypass times, high inhospital mortality (11% v. 2.1% overall), relatively longer post-operative length of stay (median 10 days, IQR 7-13), and frequent post-operative complications (51%).

STS ADULT CARDIAC SURGERY DATABASE

Review of the STS Adult Cardiac Surgery Database revealed 39,872 patients who had undergone atrial septal defect repair, pulmonary valve replacement, or other "congenital defect repair" either in isolation or along with coronary artery bypass grafting, aortic valve procedure, and/or mitral valve procedure. (During the period 2000–2009, cases coded as "congenital defect repair" were not classified with any further granularity in the STS Adult cardiac Surgery Database). Table 4 displays the patient characteristics and outcomes associated with these procedures.

DISCUSSION

This report based upon data in the STS Database analyzes the operative outcomes of the growing population of adults with congenital heart disease. The relatively young median age for adults undergoing surgery for congenital heart disease is not surprising. Many operations done in childhood are palliative and not expected to last a lifetime. Part of the increase in numbers of young adults with congenital heart disease is accounted for by the fact that survival beyond the first decade or two of life is a new phenomenon for some relatively common anomalies such as hypoplastic left heart syndrome.⁵ However, it should be noted that the patients in our primary analysis included only those entered into the STS Congenital Heart Surgery Database; thus these data are likely skewed toward younger patients undergoing surgery at congenital heart surgery centers performed by congenital heart surgeons. It has been shown previously that many ACHD patients undergo surgery at adult centers.¹⁷ These findings are confirmed in the present analysis where many more ACHD operations were entered into the STS Adult Cardiac Database vs. the Congenital Heart Surgery Database. Patients in the adult database.

The overall mortality of 2.1% for adult patients in the STS Congenital Heart Surgery Database and range of 2.1–5.0% mortality in the STS Adult Cardiac Surgery Database is within the range of previously published figures of 1.9–4.8% derived from the Nationwide Inpatient Sample,¹¹ an administrative database. Despite 31% of our overall cohort having at least one preoperative risk factor and 28% experiencing at least one postoperative complication, mortality was generally low and length of stay relatively short in the subgroups analyzed. The length of stay in our study is comparable to the 8- 10 days described in a previous report from an administrative database.¹¹ As this population continues to grow in number over the coming years, with an expected increase in the fraction of patients with complex disease having benefited from newer and more efficacious treatment strategies, continued clinical vigilance will be required to maintain and/or improve this level of morbidity and mortality.

The highest mortality in our subgroup analysis was found in those undergoing Fontan revision/conversion. Primary Fontan operation early in childhood is associated with low rates of operative mortality, with previous single institution series reporting 1–2% mortality.^{18,19} The late morbidities associated with the Fontan circulation are now being increasingly recognized. The Pediatric Heart Network Fontan study reported stroke/ thrombosis in 8%, seizures in 3%, and protein-losing enteropathy in 4% of Fontan patients approximately 8 years after the Fontan procedure.²⁰ It is not surprising that patients with declining status who are referred as adults for revision or conversion of the Fontan circulation have numerous co-morbidities and are a high risk surgical group. In the present analysis, we found that Fontan revision/conversion is associated with a mortality rate of 11%. This is higher than that reported by Mavroudis et al. in the largest single institution series published to date.²¹ Differences in the patient populations could account for the differences in mortality between that study and our analysis. Our Fontan revision/conversion

The subgroups undergoing pulmonary valve replacement and ASD repair had few preoperative risk factors and low morbidity and mortality. The mortality for pulmonary valve replacement was lower than that reported in a study from Norway, which included 79 patients over the age of 17 receiving a pulmonary valve replacement with overall early mortality of 2.7%.²² Shinkawa et al analyzed 73 patients undergoing pulmonary valve replacement and reported zero perioperative deaths.²³ Mortality for atrial septal defect repair was zero in our study and has previously been reported to be 0–1.2%.^{24,25} This is an important observation that should be considered in evaluation of innovative non-surgical means of accomplishing ASD closure.

The conduit reoperation subgroup was notable for having a high rate of preoperative neurologic deficit (4.0%). The cause of this cannot be ascertained from the data available in this study. But, our speculation to explain this finding includes a history of undergoing multiple previous cardiothoracic operations and exposure to multiple episodes of cardiopulmonary bypass. The mortality for aortic aneurysm repair in this study (2.2%) is similar to that in a single institution study from the adult cardiac literature (2.6%).²⁶ Mitral valvuloplasty carried a lower mortality (0.7%) than that reported in an Australian congenital study (4%).²⁷ This single institution Australian study, however, included younger patients (range 3 days -21 years) and all three mortality (1.9%) as a 14 year, single institution study of 160 patients.²⁸ The high rate of bleeding requiring reoperation (8.3%) in the Ross operation patients might be explained by the long cardiopulmonary time and the nature of the operation which includes many suture lines in the high pressure left ventricular outflow tract.

The results from the STS Adult Cardiac Surgery Database must be interpreted with caution. The category "congenital defect repair" potentially represents a myriad of procedures of varying complexity. There are currently limited data collected regarding diagnoses, patient characteristics, and the details of the procedures performed in the adult database such that detailed analyses are not possible. Nonetheless, it is important to consider the overall number of congenital heart surgery operations in the Adult Cardiac Surgery Database, which for the ten year period represented by these data approaches 40,000 cases. Important modifications to both the STS Congenital Heart Surgery Database, which went into effect in 2010, and the STS Adult Cardiac Surgery Database, which went into effect in 2011, will make much more detailed analyses of the entire cohort of ACHD patients undergoing surgery from either database possible. Starting in 2010, the STS Congenital Heart Surgery Database began to collect, on all patients \geq 18 years, the complete list of patient factors that are pertinent to adult patients; these factors were previously collected only in the STS Adult Cardiac Surgery Database. Starting in 2011, the complete list of congenital cardiac diagnoses and procedures is now shared by both the STS Congenital Heart Surgery Database and the STS Adult Cardiac Surgery Database.

Limitations

The limitations of this study are primarily related to the nature of the STS Database. Not all US centers participate in the STS Database or submit complete data. Thus, the results of this study may not be generalizable to ACHD patients undergoing surgery at all US centers. In addition, as noted above, our primary analysis focused on patients entered into the STS Congenital Heart Surgery Database. We found that there are many more congenital operations captured in the STS Adult Cardiac Surgery Database. As discussed,

modifications to the adult database will facilitate future detailed analyses of all ACHD operations regardless of which database they are entered into. Finally, the present analysis was primarily descriptive in nature. Detailed information regarding patient pre-operative hemodynamic status and other clinical information, in addition to center-level data regarding the presence of a dedicated adult congenital program and surgeon experience with adult congenital procedures is not currently captured in the database, and thus we were not able to include these factors in the analysis or describe their relationship with outcome.

CONCLUSIONS

This analysis of ACHD patients in the STS Congenital Heart Surgery Database offers a focused view of this emerging population. The majority comes to surgery in the third and fourth decades of life, and in-hospital mortality is low for most types of procedures. The mortality rate associated with Fontan revision/conversion is higher, which is likely related to important co-morbidities that occur in the setting of declining function of the Fontan circulation. For the entire cohort studied, post-operative complications were common, justifying further efforts to characterize and understand risk factors in the adult congenital cardiac population and processes of care that may reduce overall morbidity. Recent enhancements of the STS Databases should result in the availability of more complete and representative datasets for future analyses. Initiatives to foster collaboration of STS Adult Cardiac and Congenital Heart Surgery Databases with longitudinal ACHD registries may provide the best opportunity to evaluate long term outcomes in this patient population.²⁹

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Table 1

Study Population Characteristics

Age (years) 25 [20–35] 25 [20–35] 33 Weight(kilograms) 69 [58–83] 70 [59–86] 71 Race, Caucasian 3872 (74%) 439 (76%) 22	33 [23-46]	23 [20–29]		JE [30] 371	100 101 00	
			24 [21–31]	[10-07] 07	77 [13-70]	27 [22–33]
	71 [59–84]	67 [55–79]	78 [62–89]	66 [53–76]	73 [63–83]	68 [56–79]
	242 (66%)	262 (80%)	112 (82%)	96 (71%)	91 (84%)	84 (80%)
	131(36%)	178 (54%)	90 (66%)	38 (28%)	75 (69%)	51 (49%)
	25 (6.9%)	52 (16%)	32 (24%)	37 (27%)	7 (6.5%)	11 (10%)
Preoperative factors						
	63 (17%)	92 (28%)	25 (18%)	42 (31%)	15 (14%)	71 (68%)
	20 (5.5%)	25 (7.6%)	4 (2.9%)	16(12%)	1 (0.9%)	56 (53%)
	1 (0.3%)	5 (1.5%)	1 (0.7%)	2 (1.5%)	1 (0.9%)	1 (1.0%)
	0 (0%)	3 (0.9%)	2 (1.5%)	1(0.7%)	0 (0%)	0 (0%)
	4 (1.1%)	6 (1.8%)	0 (0%)	3 (2.2%)	0 (0%)	1 (1.0%)
	8 (2.2%)	13 (4.0%)	3 (2.2%)	4 (3.0%)	3 (2.8%)	3 (2.9%)
	1 (0.3%)	6(1.8%)	3 (2.2%)	2 (1.5%)	0 (0%)	0 (0%)
	1 (0.3%)	9 (2.7%)	4 (2.9%)	4 (3.0%)	3 (2.8%)	0 (0%)
	3 (0.8%)	8 (2.4%)	2 (1.5%)	2 (1.5%)	4 (3.7%)	3 (2.9%)

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Table 2

Operative Characteristics

•								
STS-EACTS Category								
1	2051 (39%)	1	1	1	-	1	1	;
2 1	1793 (34%)							
3	396 (7.5%)							
4 (675 (13%)							
5 (6(0.1%)							
Number of prior CT 1 operations	1 [0–2]	1 [1–2]	[0-0] 0	2 [1–3]	1 [0–2]	0 [0–1]	0 [0–1]	2 [2–3]
CPBtime(minutes) 1	117 [78–175]	91 [66–121]	61 [43–87]	109 [75–165]	172 [120–222]	120 [92–177]	195 [164–237]	195 [153–250]

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Table 3

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Outcomes

In-hospital mortality 109 (2.1%)	4 (0.7%)	0 (0%) (0%)	8 (2.4%)	3 (2.2%)	1 (0.7%)	2 (1.9%)	11(11%)
Length of stay (days) 5 [3–7]	5 [4–6]	4 [3–5]	5 [4–7]	6 [4–8]	5 [4–8]	5 [4–6]	10 [7–13]
Postoperative complication							
Any 1446 (28%)	135 (24%)	72 (20%)	96 (29%)	35 (26%)	48 (36%)	43 (40%)	54~(51%)
Arrhythmia 496 (9.4%)	39 (6.8%)	28 (7.7%)	26 (7.9%)	8 (5.9%)	22 (16%)	11 (10%)	24 (23%)
Low cardiac output 87 (1.7%)	4 (0.7%)	3 (0.8%)	5 (1.5%)	2 (1.5%)	4 (3.0%)	4 (3.7%)	9 (8.6%)
AV block requiring permanent pacer 69 (1.3%)	0 (0%)	0 (0%) (0%)	1 (0.3%)	3 (2.2%)	1 (0.7%)	2 (1.9%)	1 (1.0%)
Cardiac arrest 52 (1.0%)	2 (0.4%)	0 (0%) 0	7 (2.1%)	3 (2.2%)	1 (0.7%)	0 (0%)	3 (2.9%)
Pleural effusion 162 (3.1%)	6(1.1%)	6 (1.6%)	12 (3.7%)	4 (2.9%)	11 (8.2%)	4 (3.7%)	7 (6.7%)
Pneumonia 124 (2.4%)	19(3.3%)	12 (3.3%)	3 (0.9%)	0 (0%)	0 (0%) (0%) (0%)	1 (1.0%)	
Reintubation 71 (1.4%)	1 (0.2%)	1(0.3%)	8 (2.4%)	1 (0.7%)	2 (1.5%)	1 (0.9%)	6 (5.7%)
Mechanical ventilation>7days 52 (1.0%)	0 (0%)	2 (0.6%)	7 (2.1%)	1(0.7%)	0 (0%)	0 (0%)	6 (5.7%)
Unplanned reop 111 (2.1%)	4 (0.7%)	2 (0.6%)	6(1.8%)	4 (2.9%)	3 (2.2%)	1 (0.9%)	5 (4.8%)
Bleeding requiringreop 100 (1.9%)	7 (1.2%)	2 (0.6%)	6 (1.8%)	4 (2.9%)	1 (0.7%)	9 (8.3%)	4 (3.8%)
Renal failure requiring temporary dialysis 56 (1.1%)	3(0.5%)	0 (0%) (0%)	4 (1.2%)	0 (0%)	0 (0%)	0 (0%)	9 (8.6%)

Postoperative complications occurring in $>\!1.0\%$ of the study population are displayed.

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ASD=atrial septal defect; AV=atrioventricular; reop=reoperation

Table 4

STS Adult Cardiac Surgery Database

	ASD repair(n=26,117)	Congenital defect repair(n=10,133)	ASD repair(n=26,117) Congenital defect repair(n=10,133) Pulmonary valve replacement(n=3622)
Isolated procedure	9602(37%)	2835(28%)	1738(48%)
Age (years)	48 [36–59]	44 [32–58]	38 [28–49]
In-hospital mortality	2.1%	3.7%	2.8%
Concomitant procedure*	16,515(63%)	7298(72%)	1884(52%)
Age (years)	66 [56–75]	65 [54-74]	47 [37–56]
In-hospital mortality	5.0%	4.5%	3.5%

* Concomitant procedure=procedure performed in association with coronary artery bypass grafting, aortic valve procedure, and/or mitral valve procedure

Continuous variables are presented as median [interquartile range]

ASD=atrial septal defect