

**Executive Summary – Public Data Available on the STS Website:
The Society of Thoracic Surgeons Congenital Heart Surgery Database
Third Harvest – (1998-2002)**

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YOU ARE VIEWING THE DATA SUMMARY SECTION OF THE DATA ANALYSES OF THE SOCIETY OF THORACIC SURGEONS CONGENITAL HEART SURGERY DATABASE – THIRD HARVEST (1998—2002). THE LESION SPECIFIC SECTION OF THE REPORT IS AVAILABLE TO SITES THAT ARE MEMBERS OF THE CONGENITAL HEART SURGERY DATABASE AND SUBMIT DATA TO THE STS DURING HARVEST PERIODS.

Introduction

This participant-specific report is unique to your organization. The data included in this report were collected up to and during the 2003 harvest of the Society of Thoracic Surgeons (STS) Congenital Heart Surgery Database, the third harvest of this database. Cardiac surgical procedures performed with or without cardiopulmonary bypass performed between 1998 and 2002 are included in the report. Data for all or some of this five-year procedure capture window were submitted for this time period by 18 centers. All harvested data were put through identical data quality programs to bring them in line with the data definitions that were current at the time of the 2003 harvest (version 2.30).

Although improvements are evident, missing data values remain an issue for the database. Similar to the 2002 report, Mortality Prior to Discharge was determined to be the most reliable measure of mortality for this report. Data from other mortality fields (30 Day Status, Operative Mortality, and Mortality Assigned to this Operation) were not complete enough for meaningful analysis. Mortality Prior to Discharge was missing for 11% of the records in this report (down from 14% for the 2002 report). On a more positive note, for the field Mortality Prior to Discharge, only 3 out of 18 sites (16.7% of sites) had over 4.3% missing data. All of the remaining 15 centers (15/18 = 83.3%) had greater than or equal to 95.7% complete data in this field and 10/18 sites had 100% complete data for this field. Our analysis of mortality did not include any cases where the Discharge Status field was not completed. Furthermore, we excluded from mortality analysis all of the cases from the three centers with predominantly missing mortality data. If a patient had more than one operation during a hospitalization, assignment of mortality was made to the first operation of the given hospitalization.

A substantial amount of missing values also occur in the Non-cardiac Abnormality and Risk Factor sections; 30% of records in this report contain no information on non-cardiac abnormalities (down from 44% in the 2002 report) and 31% of records contain no information on preoperative risk factors (down from 44% in the 2002 report). Diagnosis data were missing from 7% of records (down from 11%) and Procedure data were missing from 8% (down from 12%). Although the improvements in data completeness are encouraging, we hope that this report will alert our contributing centers to the necessity of mandatory data field completion, and help us to develop appropriate strategies for more complete data collection and presentation of the data in the future.



Software improvements will help achieve more complete data. Optimal performance from systems of nomenclature and a database can be expected in an environment where the database, or system for entry of data, has certain standard regulations and requirements. The person entering the data, the nomenclature coder, must be forced to choose from the choices in the list of nomenclatures, and not be allowed to type free text directly into the fields for “Diagnoses” and “Procedures”. A separate “Comments” field can then allow further free text to add additional description to any individual diagnosis or procedure that has been chosen. The STS Congenital Database will mandate that the fields for “Diagnoses” and “Procedures” follow the above rules and do not accept free text. Until all user software is updated to comply with this regulation, we urge database participants to use the choices in the nomenclature drop-down menus and avoid the alternative of a write-in diagnosis or procedure, which, for purposes of analysis, becomes missing data.

The STS Congenital Database now mandates that the database software **REQUIRES** the input of a **PRIMARY DIAGNOSIS** and a **PRIMARY PROCEDURE** for each operation. During the 2002 Harvest (the second harvest (1998-2001) of the Society of Thoracic Surgeons (STS) Congenital Heart Surgery Database), the software analyzed the first diagnosis and procedure entered as the primary diagnosis or procedure. The STS Congenital Heart Database Task Force urged all participants to enter the first diagnosis and procedure as a choice from the drop-down menu and never as free text, with the first entry indicating the primary diagnosis or procedure. In the current 2003 Harvest (The third harvest (1998-2002) of the Society of Thoracic Surgeons (STS) Congenital Heart Surgery Database), the designation of a **PRIMARY DIAGNOSIS** and a **PRIMARY PROCEDURE** is required and the user is required to select a choice from the drop-down menu and never use free text. For this current report, DCRI actually used the primary diagnosis or procedure when assigning cases to diagnostic and procedural groups in the Data Summary Section. The assignments made in the Lesion Specific Reports were based on the inclusionary and exclusionary criteria.

Finally, future versions of the STS Congenital Database will request that the coding of diagnoses and procedures avoid the terms ending in “Not otherwise specified” (NOS). We ask all participants to code these diagnostic and procedural terms to more detail. For example, the term “TGA, NOS” should not be utilized – instead, one should specify whether the diagnosis is actually “TGA, IVS” or “TGA, VSD” or “TGA, VSD-LVOTO” etc. This will add much greater clarity for diagnostic groups such as TGA, where at present TGA NOS is the most prevalent diagnosis.

The improvements in data completeness are encouraging. Software improvements will support the continuation of this positive trend. We hope that this report will serve as motivation to strive to obtain complete data.



Report Organization

Data Summary Section: Contains overall information on patient and procedure volume, discharge mortality and procedural complexity organized by de-identified participant site and by age groupings. This section also displays the frequency of all diagnoses and procedure types in the database.

Future versions of this report will include a site-specific data summary section that will parallel the aggregate data summary section and will contain a summary of all diagnoses and procedures and mortality for each site.

Lesion Specific – Site Specific Section: Contains site-specific and national data on demographics, preoperative risk factors, non-cardiac abnormalities, features of repair, operative information, and surgical outcomes and complications.

The nine specific lesions analyzed:

- 1 - Atrial Septal Defect (ASD)
- 2 - Ventricular Septal Defect (VSD)
- 3 - AV Canal (AVC)
- 4 - Tetralogy of Fallot (TOF) Palliation
- 5 - Tetralogy of Fallot (TOF) Repair
- 6 - Aortic Stenosis and Insufficiency (ASAI)
- 7 - Hypoplastic Left Heart Syndrome (HLHS)
- 8 - Transposition of the Great Arteries (TGA)
- 9 - Coarctation of the Aorta (COA)

Missing Data Summary: Displays site and national levels of missing diagnosis, procedure, preoperative risk factor, non-cardiac abnormality and mortality data.

How to Read This Report

Mortality: Because mortality status at discharge is the chosen measure of mortality for the Congenital Heart Surgery Database analysis report, records with a missing value for discharge mortality and sites for which the level of missing mortality status at discharge exceeded 10% were removed *from mortality analyses*. These records were included in all other areas of the report. If a patient had more than one operation during a hospitalization, assignment of mortality was made to the first operation of the given hospitalization.

Site Volume: For the Data Summary Section of the report, sites are assigned to case volume categories. Please note that only operation types “CPB” and “No CPB Cardiovascular” are included in site volume categorizations and in all the



analyses in this report. Operations coded as operation type “CPB Standby” are converted to operation type “No CPB Cardiovascular” by the software vendor prior to analysis. Other operation types (“ECMO”, “CPS”, “Minor Procedure”, “Bronchoscopy”, “Other Endoscopy” “Thoracic”, “Interventional Cardiology” and “Other”) are not included in site volume categorizations and in all the analyses in this report. Sites are categorized as *low volume* if they perform up to 100 cases per year on average, *medium volume* if they perform between 101 and 250 cases per year on average and *high volume* if they perform more than 250 cases per year on average.

Comparison of Site to Overall STS: While we encourage participants to focus on how their results compare with the national STS results, a few words of caution are needed: 1) There is a wide range of volume of procedures submitted among participants. Those participants with low volume must be aware that their measured results are less stable compared to those from a high volume participant. 2) It must be noted that the current STS congenital heart surgery data have not been validated.

Lesions represented in the Lesion Specific Section: Due to the large number of congenital heart surgery disease entity types and subtypes, the STS Congenital Heart Surgery Database Taskforce chose to report on the eight most common disease entities representing ~80% of the cases in the database: atrial septal defect, ventricular septal defect, atrioventricular canal defect, coarctation of the aorta, transposition of the great arteries, hypoplastic left heart syndrome, tetralogy of Fallot (two reports, one for palliative procedures, one for repair), and aortic stenosis-aortic insufficiency.

Case Selection for Lesion Specific Section: For each lesion-specific section, an operation was included if it met the defined inclusion criteria for that section. The inclusion criteria specify which procedures and diagnoses are required to be present or may be present for each section. The list of diagnoses and procedures used in this case selection is located on the first page of each lesion-specific section. These criteria were designed to identify populations that are analytically comparable across sites. Because of this, the number of, for example, ASD cases reflected in the ASD section of the report will likely not match the overall number of ASD cases in your site’s raw data.

Risk Factors, Non-cardiac Abnormalities and Complications: The five most prevalent risk factors and the three most prevalent non-cardiac abnormalities for each lesion are reported. **Note:** *these sets of risk factors and abnormalities are determined for the entire database following each harvest. For this reason, the specific risk factors and abnormalities included in the report for a particular lesion may differ from year to year.* The ten complications reported for all lesions were those determined to be of the most clinical interest and the most objectively measured. These complications are: Unplanned reoperation, cardiac arrest, mechanical circulatory arrest, AV block requiring permanent pacemaker, sternum



left open, acute renal failure requiring dialysis, reoperation for bleeding, mediastinitis, neurologic deficit, and new onset seizures.

Mean Basic Complexity Score and Level: The Mean Basic Complexity Score and the Mean Basic Complexity Level are measures of procedural complexity that were developed by the EACTS/STS Aristotle Committee and are based on mortality potential, morbidity potential and technical difficulty. The score and the level are presented in the Data Summary section of the report. An overview of the score and the level values and their interpretation is presented in Appendix A.

