Pediatr Cardiol (2007)
DOI 10.1007/s00246-006-1447-4

Nomenclature and Databases — The Past, the Present, and the Future

A Primer for the Congenital Heart Surgeon

Jeffrey Phillip Jacobs · Constantine Mavroudis · Marshall Lewis Jacobs · Bohdan Maruszewski · Christo I. Tchervenkov · Francois G. Lacour-Gayet · David Robinson Clarke · J. William Gaynor · Thomas L. Spray · Hiromi Kurosawa · Giovanni Stellin · Tjark Ebels · Emile A. Bacha · Henry L. Walters III · Martin J. Elliott

Received: 27 June 2006 / Accepted: 5 September 2006

Abstract This review discusses the historical aspects, current state of the art, and potential future advances in the areas of nomenclature and databases for congenital heart disease. Five areas will be reviewed: (1) common language = nomenclature, (2) mechanism of data collection (database or registry) with an established uniform core data set, (3) mechanism of evaluating case complexity, (4) mechanism to ensure and verify data completeness and accuracy, and (5) collaboration between medical subspecialties.

During the 1990s, both the Society of Thoracic Surgeons (STS) and the European Association for Cardiothoracic Surgery (EACTS) created congenital heart surgery outcomes databases. Beginning in 1998, the EACTS and STS collaborated in the work of the International Congenital Heart Surgery Nomenclature and Database Project. By 2000, a common congenital heart surgery nomenclature, along with a common core minimal data set, were adopted by the EACTS and the STS and published in the *Annals of Thoracic Surgery*. In 2000, the International Nomenclature Committee for Pediatric and Congenital Heart Disease was established; this committee eventually evolved into the International Society for Nomenclature of Paediatric

J. P. Jacobs (✉)
The Congenital Heart Institute of Florida (CHIF),
All Children's Hospital, Children's Hospital of Tampa,
University of South Florida, Cardiac Surgical Associates,
603 Seventh Street South, Suite 450,
St. Petersburg, FL 33701, USA
e-mail: JeffJacobs@msn.com

C. Mavroudis
Children's Memorial Hospital, Northwestern University
Feinberg School of Medicine, Chicago, IL, USA

M. L. Jacobs
St. Christopher's Hospital for Children, Drexel University
College of Medicine, Philadelphia, PA, USA

B. Maruszewski
Children's Memorial Health Institute, Warsaw, Poland

C. I. Tchervenkov
Montreal Children's Hospital, McGill University, Montreal,
Canada

F. G. Lacour-Gayet · D. R. Clarke
Denver Children's Hospital, University of Colorado School
of Medicine, Denver, CO, USA

J. W. Gaynor · T. L. Spray
Cardiac Surgery, Children's Hospital of Philadelphia,
Philadelphia, PA, USA

H. Kurosawa
Heart Institute of Japan, Tokyo Women's Medical
University, Tokyo, Japan

G. Stellin
University of Padova Medical School, Padova, Italy

T. Ebels
Groningen University Medical Centre, Groningen
The Netherlands

E. A. Bacha
Department of Cardiology, Children's Hospital, Boston,
MA, USA

H. L. Walters, III
Department of Surgery, Wayne State University School of
Medicine, Children's Hospital of Michigan, Detroit, MI,
USA

M. J. Elliott
Cardiac Unit, Great Ormond Street Hospital for Children,
London, UK

and Congenital Heart Disease (ISNPCHD). The working component of ISNPCHD is the International Working Group for Mapping and Coding of Nomenclatures for Paediatric and Congenital Heart Disease, also known as the Nomenclature Working Group (NWG). By 2005, the NWG cross-mapped the EACTS–STS nomenclature with the European Paediatric Cardiac Code of the Association for European Paediatric Cardiology and created the International Paediatric and Congenital Cardiac Code (IPCCC) (www.IPCCC.NET).

This common nomenclature (IPCCC), and the common minimum database data set created by the International Congenital Heart Surgery Nomenclature and Database Project, are now utilized by both EACTS and STS; since 1998, this nomenclature and database have been used by both the STS and EACTS to analyze outcomes of more than 75,000 patients. Two major multi-institutional efforts have attempted to measure case complexity; the Risk Adjustment in Congenital Heart Surgery-1 and the Aristotle Complexity Score. Efforts to unify these two scoring systems are in their early stages but are encouraging. Collaborative efforts involving the EACTS and STS are under way to develop mechanisms to verify data completeness and accuracy. Further collaborative efforts are also ongoing between pediatric and congenital heart surgeons and other subspecialties, including pediatric cardiac anesthesiologists (via the Congenital Cardiac Anesthesia Society), pediatric cardiac intensivists (via the Pediatric Cardiac Intensive Care Society), and pediatric cardiologists (via the Joint Council on Congenital Heart Disease). Clearly, methods of congenital heart disease outcomes analysis continue to evolve, with continued advances in five areas: nomenclature, database, complexity adjustment, data verification, and subspecialty collaboration.

Keywords Database · Nomenclature · Complexity-adjustment · Data verification · Cardiac surgical · Outcomes analysis · Congenital heart disease · Congenital heart surgery

Introduction

Efforts are ongoing to improve the techniques and technologies available to evaluate the outcomes of treatments for congenital heart disease. The rationale for this goal is multifactorial. The techniques and technologies of outcomes analysis for congenital heart disease can function as tools to support a variety of purposes:

1. Patient care for the 1 million new patients born worldwide each year with congenital heart disease (130,013,274 births per year estimated for 2005 [11] with 8 children per 1000 births with congenital heart disease = 1,040,106 new patients each year with congenital heart disease)
2. Research
3. Teaching
4. Practice management
5. Physician-driven resource allocation
6. Physician-driven outcomes analysis
7. Health care quality improvement initiatives

During the 1990s, both the Society of Thoracic Surgeons (STS) and the European Association for Cardiothoracic Surgery (EACTS) created congenital heart surgery outcomes databases [13, 35, 36]. In 1998, the first reports of the STS National Congenital Heart Surgery Database Committee were published [35, 36] and included data from 24 centers that joined the program at various dates of entry between 1994 and 1997. There were 18,894 enrolled patient records, from which 8149 patient records were used to compile the relevant clinical features of 18 congenital heart categories during the 4-year period. Outcome data included multiple fields such as operative death, complications, and length of stay. Outcome analyses were segregated for age or weight at operation where appropriate, which varied from diagnosis to diagnosis. The data analysis was largely descriptive in character. During the same time period, the European Congenital Heart Defects Database was founded through the European Congenital Heart Surgeons Foundation. The European Congenital Heart Surgeons Foundation has since been renamed the European Congenital Heart Surgeons Association (ECHSA) and this European Congenital Heart Surgery Database is now jointly operated by the ECHSA and the EACTS. By 1995, this European Congenital Heart Defects Database had collected data from 31 centers representing 18 countries. This dataset included the entire data set from 4 countries and gathered data on more than 10,000 patients in the first 2 years. Uniform software was utilized for data collection, but the state of the art of database software at that time was problematic. Like the first report of the STS National Congenital Heart Surgery Database Committee, data analysis was largely descriptive in character. Furthermore, the data set was difficult to manage.

Events at Bristol, England [33], Denver, Colorado [10, 28, 38, 39, 41, 43, 45], and Winnipeg, Canada [42] have clearly demonstrated the importance of physician-driven outcomes analysis. For example, the

Bristol Report presents the results of the inquiry into the management of the care of children receiving complex cardiac surgical services at the Bristol Royal Infirmary between 1984 and 1995 and relevant related issues. Approximately 200 recommendations are made, many of which relate to the need for accurate multi institutional outcomes databases to quantitate outcomes of care rendered to patients with congenital heart disease, Perhaps less well-known than the Bristol Report, the Report of the Manitoba Pediatric Cardiac Surgery Inquest presents data from an inquest involving 12 children who died while undergoing, or soon after having undergone, cardiac surgery at the Winnipeg Health Sciences Centre in 1994. Clearly, these events demonstrate the importance of a meaningful and fair method of multiinstitutional outcomes analysis for congenital heart surgery.

The early multiinstitutional EACTS and STS congenital cardiac registries of the 1990s demonstrated that five primary requirements exist to allow this type of database system to facilitate meaningful multiinstitutional outcomes analysis.

1. Common language = nomenclature
2. Mechanism of data collection (database or registry) with an established uniform core data set
3. Mechanism of evaluating case complexity
4. Mechanism to ensure and verify data completeness and accuracy
5. Collaboration between medical subspecialties

This article presents the ongoing efforts by the EACTS–STS Joint Congenital Heart Surgery Nomenclature and Database Committee to meet these five requirements.

Common Language = Nomenclature

On September 19, 1998, the International Congenital Heart Surgery Nomenclature and Database Project was created to address the first two items in the previous list. A common nomenclature, along with a common core minimal data set, was adopted by the STS and EACTS and published in 2000 in the *Annals of Thoracic Surgery* [37]. The thrust toward the establishment of an international nomenclature is now being developed further by the International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD). The work is undertaken specifically by its subcommittee, the International Working Group for Mapping and Coding of Nomenclatures for Paediatric and Congenital Heart Disease, known more briefly as the Nomenclature Working Group (NWG) [1, 2, 5–8]. The need for the NWG became evident since, in 2000, almost simultaneously with the publication of the nomenclature of the International Congenital Heart Surgery Nomenclature and Database Project, the Association for European Paediatric Cardiology (AEPC) also published a suggested nomenclature system named the European Paediatric Cardiac Code (EPCC).

Members of the AEPC, EACTS, and STS quicky realized that these two nomenclature systems were complementary and not competitive. Therefore, in Frankfurt, Germany, on October 6, 2000, at a meeting attended by representatives of AEPC, EACTS, and STS, as well as multiple other societies, the International Nomenclature Committee for Pediatric and Congenital Heart Disease was founded; this committee eventually evolved into ISNPCHD.

Both the nomenclature system devised by the International Congenital Heart Surgery Nomenclature and Database Project and that suggested by the AEPC include short list and a long list. The short lists facilitate the creation of multiinstitutional outcomes registries. The long lists support the creation of echocardiographic software, academic databases, and the electronic medical record. A cross-map of the short lists was presented at the First International Summit on Nomenclature for Congenital Heart Disease at the Third World Congress of Pediatric Cardiology and Cardiac Surgery in Toronto, Canada, on May 27, 2001, and was subsequently published [1, 2, 5–8]. At this summit, the NWG was created. Between 2002 and 2005 inclusive, the NWG held seven meetings (totaling 33 full days of work) in order to cross-map the long lists and develop a single ''super-tree'' of nomenclature, to be termed the International Paediatric and Congenital Cardiac Code (IPCCC). The IPCCC and cross-map of the long lists was presented at the Fourth World Congress of Pediatric Cardiology and Cardiac Surgery in Buenos Aires, Argentina, on September 19, 2005. This system of nomenclature is available free of charge via the Internet at www.IPCCC.NET [12]. At this Web site, one may download the short lists and long lists of the IPCCC. Three versions of the IPCCC are available:

1. The version of the IPCCC derived from the nomenclature of the International Congenital Heart Surgery Nomenclature and Database Project of the EACTS and the STS
2. The version of the IPCCC derived from the nomenclature of the EPCC of the AEPC
3. The version of the IPCCC derived from the nomenclature of the Fyler Codes of Boston Children's Hospital and Harvard University.

The EACTS–STS-derived version of the IPCCC has been utilized in a variety of settings, including the following research studies:

1. A multiinstitutional study of functionally single ventricle via the Pediatric Heart Network
2. The Centers for Disease Control and Prevention (CDC) birth surveillance research study in which the Metropolitan Atlanta Congenital Defects Program reclassified more than 11,000 patients according to the EACTS-STS derived version of the IPCCC.
3. A National Institutes of Health grant examining the relationship of air pollution to the development of congenital cardiac malformations in the fetus (R01ES012967)
4. The National Institutes of Health-funded multi-institutional trial of right ventricular vs. modified Blalock–Taussig shunt in infants with single ventricle defect undergoing staged reconstruction (single ventricle reconstruction trial) conducted by the Pediatric Heart Network

In Europe, the AEPC-derived version of the IPCCC has also been utilized in a variety of settings, including the following research studies:

1. In the United Kingdom, the United Kingdom Central Cardiac Audit Database (UKCCAD) uses the AEPC-derived version of the IPCCC short list as the basis for its national, comprehensive, validated, and benchmark-driven audit of all pediatric surgical and transcatheter procedures undertaken since 2000.
2. In Germany, internal quality control for all centers is based on the AEPC-derived version of the IPCCC. The Nationale Register für angeborene Herzfehler in Berlin uses the AEPC-derived version of the IPCCC for coding all patients with congenital heart disease. The Kompetenznetz angeborene Herzfehler uses the AEPC-derived version of the IPCCC for a nation-wide scientific network supported by the German government for various specific studies, such as on right ventricular function, pulmonary hypertension, tetralogy of Fallot, and interatrial communication.
3. In the Netherlands, the national registry of congenital heart disease, CONCOR (Congenital Corvitia), uses the AEPC-derived version of the IPCCC.
4. The Swiss pediatric cardiology society uses the AEPC-derived version of the IPCCC for quality control between centers.

The NWG has also published separate specific manuscripts describing in detail the IPCCC for the controversial lesions of the functionally univentricular heart (single ventricle lesions) [14] and hypoplastic left heart syndrome [40]. These two manuscripts exemplify the efforts of the NWG to create a comprehensive and all-inclusive international system of nomenclature for pediatric and congenital heart disease, the IPCCC.

Mechanism of Data Collection = Database

The common nomenclature and common minimum database data set, created by the International Congenital Heart Surgery Nomenclature and Database Project, are now utilized by both EACTS and STS. Since 1998, this nomenclature and database have been used by both the STS and EACTS to analyze outcomes of more than 75,000 patients. A huge amount of data has been generated, which allows comparison of practice patterns and outcomes analysis between Europe and North America [15–21, 23]. A 2005 joint report of the EACTS and STS congenital heart surgery databases includes 18,928 eligible patients from the STS (3988 neonates, 6152 infants, and 8788 older patients) and 21,916 eligible patients from the EACTS (4273 neonates, 73l6 infants, and 10,327 older patients) [15]. Table 1 shows the aggregate data for all patients, documenting the number of eligible patients, discharge mortality, and Aristotle Basic Complexity Score (ABC Score) (The ABC Score is discussed in the next section of this manuscript). These data are then presented by patient age group. As one would expect, neonates have the highest mortality and complexity, followed by infants and then older patients.

Table 1 EACTS and STS aggregate data

	All	0 – 28 days	29 days – 1 year	Other
STS				
Eligible patients	18,928	3988	6152	8,788
Discharge mortality	825	487	202	136
Discharge mortality %	4.4	12.2	3.3	1.5
Basic complexity score	7.1	8.6	7.0	6.5
EACTS				
Eligible patients	21,916	4273	7316	10,327
Discharge mortality	1094	514	377	206
Discharge mortality %	5.4	13.3	5.56	2.1
Basic complexity score	6.5	7.6	6.6	5.9

These data represent surgical operations performed between 1998 and 2004 inclusive [15, 16, 17, 18]

The aggregate data from the first 5 years of data collection not only make for interesting comparisons but also allow examination of regional difference in practice patterns. For example, in the EACTS database, out of 4273 neonates undergoing cardiac surgery, 885 (20.7%) underwent arterial switch procedures and 297 (6.95%) underwent Norwood stage I procedures. In the STS database, out of 3988 neonates undergoing cardiac surgery, 472 (11.8%) underwent arterial switch procedures and 575 (14.4%) underwent Norwood stage I procedures.

The recent EACTS and STS analysis of the combined 40,844 patients produced a huge amount of data, some of which have been published on the Internet (www.sts.org, accessed April 1, 2006; and www.echsa.org accessed April 1, 2006) and in print [15–21, 23]. This database continues to evolve, with major efforts continuing in the following four areas:

1. Standardizing the methodology of evaluating case complexity
2. Creating a mechanism to ensure and verify data completeness and accuracy
3. Developing standardized protocols for congenital heart disease outcomes analysis that are accepted by surgeons, cardiologists, intensivists, and anesthesiologists
4. Improving the level of national and international database participation

Mechanism of Evaluating Case Complexity

The importance of the quantitation of case complexity centers on the fact that in the field of pediatric cardiac surgery, outcomes analysis using raw mortality measurements without complexity adjustment is inadequate. Case mix can vary greatly from program to program. Without complexity adjustment, programs caring for the most complex patients may be reluctant to participate in multiinstitutional outcomes database. Two major multiinstitutional efforts have attempted to measure case complexity.

A consensus-based risk-adjusted scheme for congenital heart surgery called Risk Adjustment in Congenital Heart Surgery-1 (RACHS-1) was developed in Boston in order to stratify procedures for congenital heart disease. The RACHS-1 method ''was created to allow a refined understanding of differences in mortality among patients undergoing congenital heart surgery, as would typically be encountered within a pediatric population'' [24]. Previous publications have clearly documented the ''underlying assumptions about RACHS-1 risk categories, inclusion and exclusion criteria, and appropriate and inappropriate uses'' of RACHS-1 [24]. This RACHS-1 system is procedure driven and divides all procedures into six groups (1–6, with 1 indicating easy and 6, indicating difficult) [3, 24–27, 29, 44]. The RACHS-1 system has been demonstrated to be a useful tool in several studies in both Europe and North America and represents one of the first widely accepted complexity adjustment tools developed in our field. Both the EACTS and the STS now incorporate the RACHS-1 system into their multi-institutional anylyses. Initial data from these multi-institutional databases indicates that the RACHS-1 system correlates well with mortality prior to discharge from the hospital after congenital heart surgery.

In 1999, the Aristotle Committee was created to address the issue of complexity adjustment in congenital heart surgery [20, 30–32, 44]. This group was composed of a panel of experts composed of 50 surgeons repairing congenital cardiac malformations in 23 countries and representing multiple societies, including the Congenital Heart Surgeons' Society (CHSS), EACTS, the European Congenital Heart Surgeons Association (ECHSA; formerly known as the European Congenital Heart Surgeons Foundation) and STS. The ABC Score allocates a basic score to each operation, varying from 1.5 to 15 (with 15 being the most complex) based on the primary procedure of a given operation as selected from the short list of the nomenclature of the International Congenital Heart Surgery Nomenclature and Database Project. The Aristotle Basic Complexity Level (ABC Level) allocates an integer from 1 to 4 (with 4 being the most complex), also based on the primary procedure of a given operation as selected from the short list of the nomenclature of the International Congenital Heart Surgery Nomenclature and Database Project. The basic score was calculated using the three factors of the potential for mortality, the potential for morbidity, and the technical difficulty of the operation. Both EACTS and STS now incorporate the ABC Score into their multiinstitutional analyses. Initial data from these multiinstitutional databases indicate that the ABC Score and the ABC Level correlate well with mortality prior to discharge from the hospital after congenital heart surgery (Fig. 1). Efforts are ongoing to validate the ABC score and to evaluate the Aristotle Comprehensive Complexity Score (ACC Score), which adds to the ABC Score by incorporating two sorts of patient-specific complexity modifiers: procedure dependent factors (including anatomical factors, associated procedures, and age at procedure) and procedure–independent factors (including general factors, clinical factors, extracardiac factors, and surgical factors).

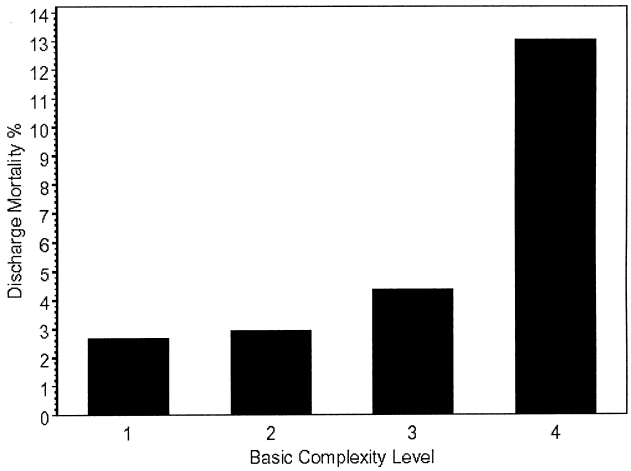

Fig. 1 This Graph plots the Aristotle Basic Complexity Level against discharge mortality and demonstrates the expected relationship of increasing mortality with increasing complexity based on data from the 2002 STS congenital data harvest utilizing data from 16 centers (12,787 total cases, 2881 neonatal cases, and 4124 infant cases). These data represent surgical operations performed between 1998 and 2001 inclusive [16, 23]

The Aristotle Committee is currently involved in ongoing research to validate this complexity adjustment scoring system on a multiinstitutional basis.

The ABC Score has been utilized as a measure of case complexity in the databases of EACTS, STS, and UKCCAD. Research is ongoing to validate the ABC Score within these multiinstitutional registries. Figs 2–4 depict graphs derived from the EACTS database (30,041 operations from 63 centers), the STS database (27,820 operations from 34 centers), and the UKCCAD (3666 operations from 13 centers), respectively. All three graphs plot ABC Score on the x-axis and mortality on the y-axis and demonstrate excellent correlation between the ABC Score and mortality. These graphs demonstrate that the ABC Score can be applied to individual program, for performance comparison to other programs or for comparison to the average overall database performance. For an individual program, the correlation between mortality and ABC Score will differ from this relationship in the large multiinstitutional database unless the program under analysis is performing exactly at the average. Otherwise, the outcome for a given program will be either better or worse than those reflected by the ABC Score because actual outcome depends on performance. In essence, the multiinstitutional database can provide a standard for the relationship between mortality and case complexity as measured by the ABC Score. In three large multiinstitutional databases with more than 60,000 operations, the ABC Score correlates with mortality.

Evaluation of programmatic performance or individual surgeon performance in the field of congenital heart surgery cannot be done adequately utilizing measure-

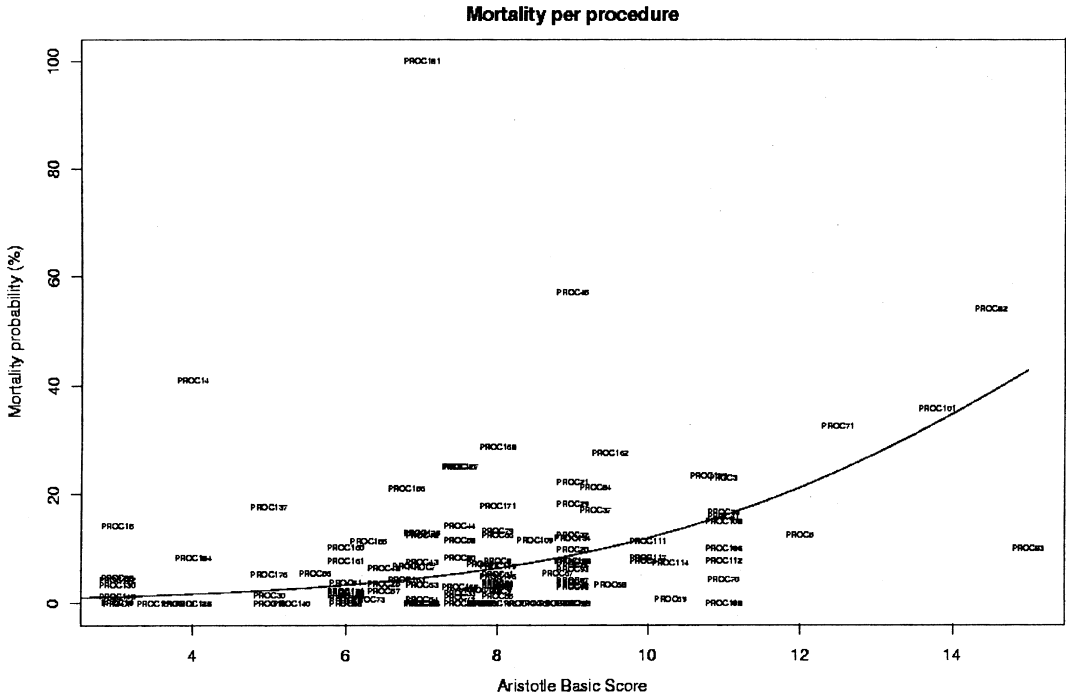

Fig. 2 EACTS data $P < 0.001$ (logit regression, Statistica for Windows version 6)

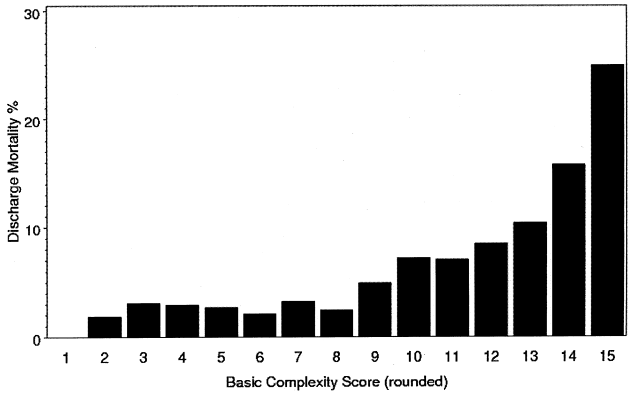

Fig. 3 STS data: This graph plots the rounded Aristotle Basic Complexity Score against discharge mortality and demonstrates the expected relationship of increasing mortality with increasing complexity based on data from the 2005 STS congenital data harvest utilizing data from 34 centers (27,820 total cases). These data represent surgical operations performed between 2002 and 2004 inclusive [19]

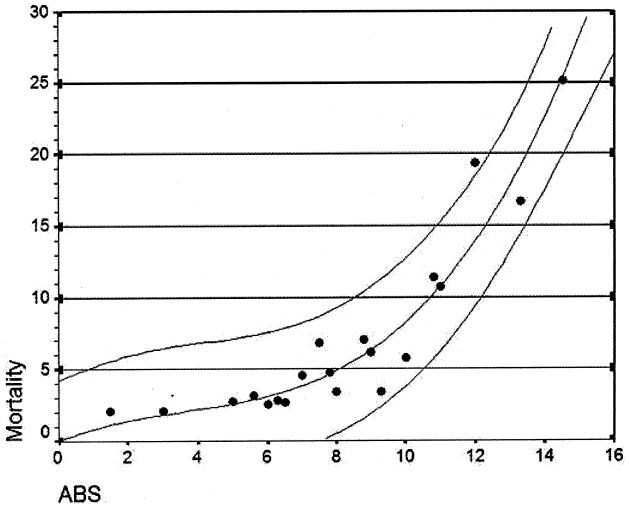

Fig. 4 UKCCAD data

ments of raw mortality alone. Case mix must be factored into the analysis. In multiple studies, both the RACHS-1 system and the ABC Score have demonstrated a strong association with both hospital mortality and length of stay in survivors; therefore, these scoring systems provide a valuable tool for complexity adjustment when comparing providers of care and/or institutions. Nevertheless, neither RACHS-1 nor ABC Score are adequate for risk adjustment for individual patient scenarios. More comprehensive tools such as the ACC Score may eventually allow for risk adjustment for individual patient scenarios.

Efforts are underway to unify the Aristotle and RACHS systems in order to benefit from the potentially complementary advantages of the two approaches. The combination of RACHS-1 and ABC score may provide more information than either system used in isolation. The potential exists to utilize known outcome data from the multiinstitutional registries to create a unified system of complexity adjustment based on both objective data when they are available and subjective probability when the objective data are lacking.

Mechanism to Ensure and Verify Data Completeness and Accuracy

In the field of congenital heart surgery, multiple international collaborative efforts are ongoing with the common goal of improving our ability to measure outcomes and care for our patients. Data quality and accuracy are central issues as we move forward. Collaborative efforts involving EACTS and STS are under way to develop mechanisms to verify data completeness and accuracy. Verification of the completeness of the data is crucial because it has been previously shown that patients not included in medical audit have a worse outcome than those included [4]. The importance of the verification of the accuracy of the data is demonstrated in a recent prospective, longitudinal, observational, national cohort survival study from the UKCCAD [9]. The UKCCAD analyzed 3666 surgical procedures and 1828 therapeutic catheterizations performed from 2000 and 2001, from all 13 UK tertiary centers performing cardiac surgery or therapeutic cardiac catheterization in children with congenital heart disease. Thirty-day mortality was identified both by volunteered life status from the hospital databases and by independently validated life status through the Office for National Statistics, using the patient's unique National Health Service number, or the general register offices of Scotland and Northern Ireland. Central tracking of mortality identified 469 deaths, with 194 occurring within 30 days and 275 later. Forty-two of the 194 deaths within 30 days (21.6% of the 30-day mortality) were detected by central tracking but not by volunteered data. In other words, hospital-based databases underreported 30-day mortality by 21.6% even though the hospitals were aware that the data would be independently verified. The authors conclude that ''independent data validation is essential for accurate survival analysis'' and that ''one-year survival gives a more realistic view of outcome than traditional perioperative mortality'' [9]. These two publications [4, 9] clearly demonstrate the importance of data verification for both completeness and accuracy.

The EACTS Congenital Heart Surgery Database [34] recently attempted to verify the data within the databases of five European Congenital Heart Surgery Centers utilizing source data verification (SDV). Pre- and post verification mortalities in all groups showed no significant differences, although 7 deaths out of 68 (10.27%) were missed. None of the other verified fields showed significant differences after verification. The authors state that SDV showed no statistically significant differences between verified and nonverified data on 30-day mortality, length of stay, age, body weight, cardiopulmonary bypass time, aortic cross-clamp time, and circulatory arrest time. The authors also state that ''an international committee of experts is needed to define common data verification methodology and to apply it in future works on outcome analysis in CHS (congenital heart surgery). Such a group has been recently established between the EACTS and STS. This is the work in progress and some feedback from this committee is expected before the end of 2005.''

This well done study by Maruszewski and colleagues [34] analyzes the data properly and appropriately discusses the limitations of the analysis. The authors honestly report that 7 deaths out of 68 (10.27%) were missed; this presentation of the ''missed mortality'' data is more honest than stating that 7 deaths out of 1895 operations (0.37%) were missed. Although the authors state that SDV showed no statistically significant differences between verified and nonverified data in the 30-day mortality fields, it is troubling that more than 10% of the 30-day mortality was not reported. Clearly, the need exists for a common methodology for data verification to be developed and implemented in all congenital heart disease outcomes registries worldwide. Furthermore, common definitions for fields such as mortality will need to be implemented into all congenital heart disease outcomes registries worldwide [22]. Collaborative efforts continue, with the goal of improving and standardizing the methodology of data verification. The STS is initiating a program of site visits for onsite data verification. A combination of site visits with SDV and external data verification from independent databases or registries, such as governmental death registries, may ultimately be required to allow for optimum data verification. Obviously, further research in the area of data verification is necessary.

Collaboration Between Medical Subspecialties

Further collaborative efforts are also ongoing between pediatric and congenital heart surgeons and other subspecialties, including pediatric cardiac anesthesiologists [via the Congenital Cardiac Anesthesia Society (CCAS)], pediatric cardiac intensivists [via the Pediatric Cardiac Intensive Care Society (PCICS)], and pediatric cardiologists [via the Joint Council on Congenital Heart Disease (JCCHD)].

The STS Congenital Database Taskforce and PCICS have had several meetings. The PCICS utilizes a database known as the VPS. PCICS has agreed to map its coding system to the EACTS–STS nomenclature; and therefore, the coding in the PCICS VPS will be compliant with the EACTS–STS nomenclature diagnosis short list and procedure short list. Collaborative projects between PCICS and STS include defining preoperative risk factors and postoperative complications and morbidity as well as sharing methodologies of complexity adjustment and data verification.

CCAS has also agreed to utilize the EACTS–STS derived version of the IPCCC and is exploring the creation of a joint CCAS–STS congenital cardiac surgery and anesthesia database. JCCHD is developing a pediatric cardiology database project that will also utilize the IPCCC.

Finally, multiple ongoing research projects involve the collaboration of many of these professional societies. For example, the task of defining perioperative complications is now the subject of the MultiSocietal Database Committee for Pediatric and Congenital Heart Disease composed of representatives of the following societies and groups:

1. The STS Congenital Database Taskforce
2. The STS Congenital Database Taskforce Core Users Group
3. The STS Congetital Database Data Verification Subcommittee
4. The EACTS Congenital Heart Committee
5. The Aristotle Institute (developers of the Aristotle Complexity Score)
6. The Multi-Center Panel of Experts for Cardiac Surgical Outcomes (developers of RACHS)
7. The Pediatric Cardiac Intensive Care Society VPS Database
8. The Congenital Cardiac Anesthesia Society Database
9. The Joint Council on Congenital Heart Disease
10. The Association of European Pediatric Cardiology
11. The Pediatric Committee of the International Consortium of Evidence Based Perfusion (ICEBP)
12. The International Working Group for Mapping and Coding of Nomenclatures for Paediatric and Congenital Heart Disease (Nomenclature Working Group)

13. The World Society for Pediatric and Congenital Heart Surgery
14. The Center for Quality Improvement and Patient Safety of Agency for Healthcare Research and Quality (AHRQ) of the United States Department of Health and Human Services
15. The Birth Defect Branch of the Centers for Disease Control and Prevention (CDC)

After focusing on perioperative complications as their project for 2006–2007, the MultiSocietal Database Committee for Pediatric and Congenital Heart Disease plans to focus on preoperative risk factors as their project for 2007–2008. These examples of collaboration across subspecialties demonstrate the reason why the professions caring for patients with congenital heart disease may be closer than any other field in medicine to creating a true global database that spans geographical and professional boundaries.

Improving the Level of National and International Database Participation

During the past 5 years, the STS Congenital Heart Surgery Database has steadily grown. Figs 5 and 6 document this growth by both number of participating centers and number of cases. Efforts are ongoing to increase the level of participation. The following ongoing projects should all lead to increased participation in the congenital database:

1. Efforts are ongoing to improve the quality of the data reports generated from the database.
2. Efforts are ongoing to further standardize the definitions used within the database. The recent publication defining operative mortality exemplifies this point [22]. Furthermore, the STS Congenital Database Taskforce Core Users Group has defined all of the elements in the STS Congenital Minimal Database (www.sts.org). Finally, the work of the MultiSocietal Database Committee for Pediatric and Congenital Heart Disease demonstrates how these definitions are applicable to multiple subspecialties and, it is hoped, will be standardized across these subspecialties.
3. The potential for improved complexity adjustment tools via the unification of RACHS-1 and ABC score may also lead to increased database participation.
4. The development of improved methods of data verification may also lead to increased database participation.

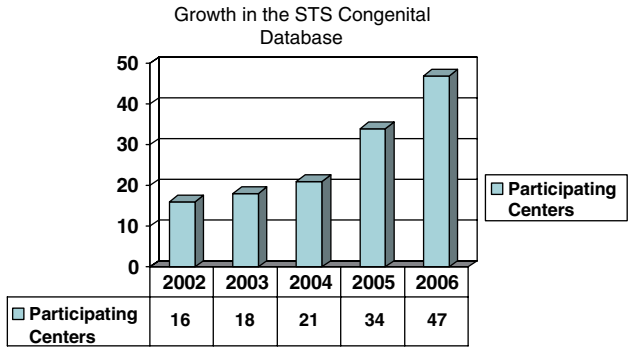

Fig. 5 Growth in the STS congenital database

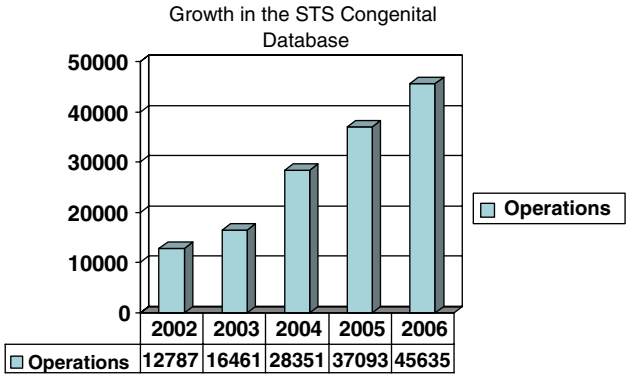

Fig. 6 Growth in the STS Congenital Database (Operations per averaged 4 year data cycle)

5. The STS Congenital Database Taskforce is exploring methods to become a source for regional congenital heart surgery outcomes reports. Initial efforts have occurred in Florida. Sponsored by the State of Florida, an STS-Florida Congenital Heart Surgery Regional Report has been created with the planned voluntary participation of all eight of the congenital heart surgery programs in Florida. This report may eventually serve as a template for other similar regional reports involving other areas of the continent and these efforts may also lead to increased STS congenital database participation.
6. The collaborative efforts that are ongoing between pediatric and congenital heart surgeons and other subspecialties, including pediatric cardiac anesthesiologists, pediatric cardiac intensivists, and pediatric cardiologists, should also lead to increased STS congenital database participation.

The major remaining challenges center on the task of improving the level of national and international database participation. Efforts are ongoing to increase involvement from Africa, Asia, Australia, and South America.

Summary

Members of The Joint EACTS – STS Congenital Heart Surgery Nomenclature and Database Committee continue to work on multiple projects to achieve further the goal of creating a multinstitutional outcomes database that meets the following five requirements:

1. Common language = nomenclature
2. Mechanism of data collection (database or registry) with an established uniform core data set
3. Mechanism of evaluating case complexity
4. Mechanism to ensure and verify data completeness and accuracy
5. Collaboration between medical subspecialties

The professions caring for patients with congenital heart disease are closer than ever to creating a true global outcomes database that spans geographical and professional boundaries.

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