Review

Congenital heart surgery nomenclature and database project: update and proposed data harvest

Bohdan Maruszewski, Francois Lacour-Gayet, Martin J. Elliott, J. William Gaynor, Jeffrey P. Jacobs, Marshall L. Jacobs, Christo I. Tchervenkov, Hiromi Kurosawa, Constantine Mavroudis,*

For the International Congenital Heart Surgery Nomenclature and Database Project and the Congenital Heart Surgery Committees of the Society of Thoracic Surgeons and the European Association for Cardio-thoracic Surgery

1Cardiac Surgery, Memorial Hospital Child's Health Centre, Warsaw, Poland
2Cardiac Surgery, Universitaetsklinikum Eppendorf, Hamburg, Germany
3Cardiothoracic Surgery, Hospital for Sick Children, Great Ormond Street, London, UK
4Division of Pediatric Cardiothoracic Surgery, The Children's Hospital at The Children's Hospital of Philadelphia, Philadelphia, PA, USA
5Division of Thoracic and Cardiovascular Surgery, All Children's Hospital, University of South Florida College of Medicine, St. Petersburg, FL, USA
6Section of Cardiothoracic Surgery, St. Christopher's Hospital for Children, Philadelphia, PA, USA
7Division of Thoracic and Cardiovascular Surgery, Montreal Children's Hospital, Montreal, Quebec, Canada
8Cardiovascular Surgery, Jikei University School of Medicine, Tokyo, Japan
9Department of Surgery, Division of Cardiovascular-Thoracic Surgery, Northwestern University Medical School, Children's Memorial Hospital, Chicago, IL, USA

Received 27 September 2001; accepted 2 November 2001

Summary

In 1998, the first report of the Society of Thoracic Surgery (STS) National Congenital Heart Surgery Database reported the clinical features of 18 congenital heart categories. The report provided a significant amount of important information and also highlighted the strengths and weaknesses of the existing database. Following this initial report, the STS Congenital Heart Surgery Committee, in cooperation with the European Association of Cardio-Thoracic Surgery and the European Congenital Heart Surgeons Foundation, initiated the International Congenital Heart Surgery Nomenclature Database Project. The first report of the International Congenital Heart Surgery Nomenclature Database Project was published in the Annals of Thoracic Surgery in April 2000. The current report outlines modifications to the minimal dataset, as well as the diagnosis and procedure short lists. © 2002 Elsevier Science B.V. All rights reserved.

Keywords: Society of Thoracic Surgery; Database; Heart surgery

In 1998, the first report of the Society of Thoracic Surgeons (STS) National Congenital Heart Surgery Database reported clinical features of 18 congenital heart categories compiled over a 4-year period using over 8000 patient records from 24 institutions [1,2]. Outcome data included operative death, complications, and length of stay. The data analysis was largely descriptive and while the report provided a significant amount of important information, it also demonstrated the strengths and weaknesses of the existing database. Following this initial report, the STS Congenital Heart Surgery Committee, in cooperation with the European Association of Cardio-Thoracic Surgery (EACTS) and the European Congenital Heart Surgeons Foundation (ECHSF), initiated the International Congenital Heart Surgery and Nomenclature Database Project. The goals of this project were to begin the standardization of nomenclature and reporting strategies and establish the foundations for an international congenital heart surgery database. The first report of the International Congenital Heart Surgery Nomenclature Project was published in the Annals of Thoracic Surgery in April 2000. The current report outlines modifications to the minimal dataset, as well as the diagnosis and procedure short lists. © 2002 Elsevier Science B.V. All rights reserved.

Keywords: Society of Thoracic Surgery; Database; Heart surgery
made recommendations for an inclusive rather than exclusive method of reporting. Two datasets for an international congenital heart surgery database were proposed: a minimal and a comprehensive dataset. The comprehensive dataset was designed to allow detailed categorization of congenital heart defects and operative procedures. The comprehensive dataset also provides the capability of extensive reporting of preoperative and postoperative variables to allow for outcomes analysis and risk stratification. The minimal dataset was designed to create an essential dataset that would be mandatory for inter-institutional data sharing and would allow elucidation of basic trends. Since the original publication, there have been several additions to the minimal dataset, as well as the diagnoses and procedure short lists (Table 1). The final minimal database dataset is comprised of 38 items (25 mandatory, 13 optional) (Appendices 1–2). Four short lists have been defined for: (1) non-cardiac abnormalities/general preoperative risk factors; (2) diagnoses; (3) procedures; and (4) complications, from which an appropriate entry can be chosen (Appendices 3–6). The minimal data entry form is described in Appendix 1 and presented in Appendix 2. The final version of the minimal dataset, as well as the short lists and modifications have been approved by the STS Congenital Heart Surgery Committee and the EACTS Congenital Heart Surgery Committee [4], as well as the ECHSF [3,4]. The appendices can be viewed at www.ctsnet.org/doc/5357.

The minimal database dataset and reporting forms have been incorporated in the CardioAccess™ International Clinical Outcomes Database (CardioAccess Inc., St. Petersburg, Florida and Fort Lauderdale, FL: http://www.cardioaccess.com). Electronic versions of the minimal dataset can be downloaded without charge from the web pages of CardioAccess (http://www.cardioaccess.com) or the STS Congenital Heart Surgery Registry (ECSUR) (www.pediatric.ecsur.org). Center and individuals interested in participating in the Pediatric ECSUR project should contact: Bohdan Maruszewski, M.D., Ph.D., Pediatric ECSUR Database Director, Cardiac Surgery, Memorial Hospital Child’s Health Centre, Warsaw, Poland. Tel./fax: +48-22-815-2754. E-mail: bmar@pol.pl or Zdzislaw Tobota, M.D., Pediatric ECSUR Database Coordinator. Tel./fax: +48-501-162-807. E-mail: echdd@pol.pl

Registration information can also be obtained at the Pediatric ECSUR website (http://www.ecsur.ic.ac.uk).

The Association of European Pediatric Cardiologists (AEPC) has independently proposed a diagnostic hierarchy for congenital heart defects, which was published in Cardiology in the Young [5]. Representatives of the AEPC, STS, EACTS, and ECHSF met during the October 2000 meeting of the EACTS in Frankfurt, Germany to discuss future collaboration. An agreement was reached for a joint committee with members from the International Congenital Heart Surgery Nomenclature and Database Project with representatives of the STS, EACTS, and ECHSF, and representatives

<table>
<thead>
<tr>
<th>Table 1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Additions to the minimal dataset</strong></td>
</tr>
<tr>
<td><strong>Minimal data set</strong></td>
</tr>
<tr>
<td>The following six fields will be added as optional fields</td>
</tr>
<tr>
<td>Race/ethnicity</td>
</tr>
<tr>
<td>(Caucasian, Black, Hispanic, Asian, Native American, other)</td>
</tr>
<tr>
<td>Zip</td>
</tr>
<tr>
<td>(Alphanumeric)</td>
</tr>
<tr>
<td>State</td>
</tr>
<tr>
<td>(Alphanumeric)</td>
</tr>
<tr>
<td>Country</td>
</tr>
<tr>
<td>(Alphanumeric)</td>
</tr>
<tr>
<td>Date/time of intubation</td>
</tr>
<tr>
<td>(form = dd/mm/yyyy h:min)</td>
</tr>
<tr>
<td>Date/time of extubation</td>
</tr>
<tr>
<td>(form = dd/mm/yyyy h:min)</td>
</tr>
</tbody>
</table>

The following fields are now mandatory:

Mortality assigned to this operation (yes or no)
Mortality discharge status (dead or alive)

**Non-cardiac abnormalities**

Add:
None
Change:
Other chromosomal abnormality
To
Other chromosomal/syndromic abnormality

**General preoperative risk factors short list**

Add:
None

**Diagnosis short list**

Add:
Cardiomyopathy, end stage congenital heart disease
Coronary artery anomaly, aneurysm
Coronary artery anomaly, anomalous aortic origin
Coronary artery anomaly, anomalous pulmonary origin (includes ALCAPA)
Coronary artery anomaly, fistula
Coronary artery anomaly, NOS
Coronary artery anomaly, other
Pulmonary artery stenosis, NOS
Pulmonary artery, discontinuous
Pulmonary stenosis, subvalvar
Truncal valve insufficiency

Change the header:
Coronary artery fistula
To
Coronary artery anomaly
Delete the header
Anomalous origin of the coronary artery
And its associated term
Anomalous origin of the coronary artery from the pulmonary artery

**Procedure short list**

Change pulmonary insufficiency header to
Pulmonary valve disease
Add:
Arrhythmia surgery, NOS
Atrial baffle procedure, NOS
Conduit placement, NOS
Ligation, pulmonary artery
Ligation, thoracic duct
Organ procurement
Other
Valve closure, semilunar
Valve excision, pulmonary (without replacement)
Valvuloplasty, truncal valve

**Complications short list**

Add:
None
Postoperative respiratory insufficiency requiring reintubation
of the AEPC, to establish a system to reconcile and map the
two coding systems. The initial step is defining equivalent
diagnoses and procedures in the short lists that are used for
the minimal dataset. To ensure that each diagnosis and
procedure in one system can be mapped to an equivalent,
it will be necessary to add terms. For example, the AEPC
hierarchy contains coding for interventional cardiology
procedures in greater detail than the STS, EACTS,
ECHSF coding. Considerable progress has been made in
merging the two coding systems.

A progress report was presented at the Third World
Congress of Pediatric Cardiology and Cardiac Surgery in
Toronto. At the Third World Congress, on May 27, 2001,
an International Summit on Nomenclature for Congenital
Heart Disease was held. Representatives from Surgical
and Cardiology Societies throughout the world participated
in this Summit including the AEPC, the EACTS, the
ECHSF, and the STS, as well as the American College of
Cardiology, the Asian Society of Cardiovascular Surgery,
the Canadian Cardiovascular Society, the Cardiology
Subsection of the American Academy of Pediatrics, and
the Council on Cardiovascular Disease in the Young of
the American Heart Association. Additional participants
included representatives from Australia, India and South
America.

The almost simultaneous publication of the EACTS/STS
coding system [3] (http://www.ctsnet.org/doc/3699) and the
AEPC coding system [5] (http://www.aepc.org/code-
com.htm) resulted in the potential for multiple coding and
a great deal of confusion. Both coding systems exist in short
and long code forms. Each was designed with a common
purpose, but for users with different needs (AEPC – cardi-
ologists, EACTS/STS – surgeons). At the International
Summit on Nomenclature for Congenital Heart Disease, it
was agreed that these two diagnostic hierarchies are comple-
mentary and not competitive. A mapping of the short lists
between the two systems was approved. It was also agreed
that an international effort should continue with the goal of
mapping the long lists and creating a single nomenclature
‘super tree’ utilizing the mapped long lists. The goal is to
create this mapped long list by the next World Congress in 4
years. An international committee made up of representa-
tives of all of the above organizations and other interested
parties has been established to achieve this goal. Centers and
individuals interested in participating in this project should
contact the committee chairman:

Martin Elliott, M.D., F.R.C.S, Consultant Cardiothoracic
Surgery, The Great Ormond Street Hospital for Children,
London WCIN3JH. Tel.: +44-02-7829-8853/fax: +44-02-
7813-8262, E-mail: ellioml@gosh.nhs.uk

References

[1] Mavroudis C (Chairman) and Congenital Database Subcommittee:
    Backer CL, Bove E, Burke RP, Cameron D, Drinkwater DC, Edwards
    FH, Grover FL, Hammon JW Jr, Jacobs JP, Kron IL, Mauer JE, Myers
    JL, Ring WS, Siewers RD, Szarnicki RJ, Watson DC Jr. Data Analyses
    of the Society of Thoracic Surgeons National Congenital Cardiac
    Surgery Database, 1994–1997, Summit Medical, Minnetonka, MN,
    September 1998.
    society of thoracic surgeons national congenital heart surgery database
database project: overview and minimum dataset. Ann Thorac Surg
    Presentation of the international nomenclature for congenital heart
    surgery: the long way from nomenclature to collection of validated
[5] Franklin RCG, Anderson RH, Daniels O, Elliott M, Gewillig MHML,
    Ghisla R, Krogmann ON, Ulmer HE, Stocker FP. Report of the coding
    committee of the Association for European Paediatric Cardiology.