Data Sources

PCCC

The Pediatric Cardiac Care Consortium [1] database contains information on all cardiac procedures – including surgeries, cardiac catheterizations, and electrophysiology studies – performed at over 40 member institutions. Each participating center signs an annual contract with the PCCC. The database contains demographic data, diagnoses and procedures, history of previous cardiac operations, and associated non-cardiac conditions. After data have been submitted, information is extracted and all diagnoses and procedures are recoded using a standardized system. Details of the creation, activities and function of the PCCC have been described in several publications [2-4]. The PCCC was formed to overcome challenges of the limited number of patients with cardiac malformations (8/1000 live births), the even rarer incidence of any particular malformation, and the limited subset of these patients that present for catheterization or surgical correction It was recognized that the experience of any one institution was limited and collaboration between centers was necessary to have sufficient numbers to conduct meaningful outcomes analysis. Data collected include patient identifier, patient country and state or country of origin, hospital name encounter, encounter identifier number, birth date, birth weight [5], hospital admission date, weight at time of admission, previous cardiac operations (types and dates), presence and type of noncardiac malformations or conditions, cardiac catheterization data, (including date, weight, hemoglobin, cardiac diagnosis, and type of procedure), discharge, transfer, or death date (including diagnoses at death). Diagnosis data include detailed cardiac diagnosis, cardiac procedure, chromosomal anomalies, and information on other systems including central nervous system (CNS), gastrointestinal (GI), genitourinary (GU), respiratory and musculoskeletal. Outcome data include 30-day survival post procedure, need for ECMO, need for pacemaker abnormalities or Automatic Implantable Cardio-Defibrillator (AICD), need for unplanned reoperation, and length of hospitalization.

Since the inception of the PCCC, the value of the database as a research tool has been well recognized. [6-12]. Few other multi-center collaborative studies exist in the field, and none include as many patients or have existed for as long a time period as the Consortium. Today, the PCCC has enrolled over 100,000 patients and has data for over 130,000 procedures (surgeries and catheter-based interventions or electrophysiologic studies) since 1982. The patient-specific longitudinal follow-up within the registry data is invaluable when assessing long-tem outcomes after operative or catheter intervention for rare CHD. Data from this multi-center registry have been presented extensively in peer-reviewed manuscripts or scientific meetings and have contributed significantly to the understanding of the long term outcomes of CHDs [6-8, 10-16]. Ideally, life expectancy rates and causes of death for the various types of procedures for CHD should come from prospective studies of large groups of patients with these conditions and their respective interventions. These studies are not feasible and therefore, the main other source of information regarding the altered history of CHD remain the clinical registries. Unfortunately, a common drawback of these registries is limited availability of long-term follow up. An alternative approach is to enrich existing clinical registries with long term data from other sources, for example, by linking them to a national death registry. Linking the PCCC with such registry would overcome this weakness in terms of providing long term mortality data and causes of death. The combined post-linking database will provide a unique resource that can be used to evaluate long-term survival

data and major causes or contributing factors of death for patients surviving interventions for CHD.

The PCCC was formed in 1982 and a 25 year experience has now been compiled in addition to several articles describing composite results for specific operations, cardiac anomalies or genetic syndromes [1, 4, 6, 7, 10-12, 17-18]. A major strength of the registry has been the ability to analyze rare congenital anomalies and their treatment in a group of cardiac centers spread across a large geographic area. The goal of the program is to assess the quality of care being given to infants and children with cardiac conditions; reports are issued on an annual basis. To assure data quality, the PCCC coders manually review all cardiac diagnosis and procedure codes for consistency among institutions; a double data entry process is employed; and independent verification of the number of procedures performed at each institution in a given year is obtained.

A. Overview. Currently, each center registers individuals into the PCCC with a paper form faxed or mailed to the University of Minnesota (data entered on the form is listed in Table 1). The information is then entered into the computer twice to reduce entry errors. A review is undertaken each year to resolve data conflicts and to ensure data completeness. Descriptive statistics are used to describe the annual occurrence number and type of patients, mix of services, cardiac catheterization experience, operative experience, mortality, and length-of-stay. A statistical test of significance [20] is used to note differences between an individual center and the group. An executive summary is prepared for each center. Each center receives a report summarizing the center's adjusted mortality for each of the procedures for which they have had 10 cases during the past 5 years. For each of these operations, a separate report is included, depicted the mean and range of values for the individual center, including the nine variables predictive of mortality. This allows a center to compare their experience with the group particularly for operations for which they have an elevated adjusted mortality.

The coding system used by the PCCC was created after reviewing various classification schemes for congenital heart disease, including The International Classification of Diseases [21] and that of the World Health Organization. These were found to be either too broad or imprecise to be clinically useful. Therefore, a new coding system was developed that included separate codes for diagnoses and procedures. The coding system was developed with the goal to provide detailed description of the cardiac lesion evaluate the complexity of the operation, ensure the completeness of the data and create a platform for collaboration between medical and surgical disciplines. Codes are 5 digits in length, with each additional digit defining more precise anatomy and surgical intervention. For example, a diagnosis code of 13100 indicates an atrial septal defect; 13120 indicates a secundum-type atrial septal defect; and 13121 indicates a secundum atrial septal defect with a left-to-right shunt. This allows one to search for all diagnoses or procedures included in general categories (i.e. all 131xx codes to capture all atrial septal defects) or to search specifically for very narrow diagnoses (i.e. only secundum atrial septal defects).

Participating centers agree to submit data on all patients treated at their institutions and to permit independent confirmation on the number of procedures performed annually to ensure compliance. Centers also agree to pay a nominal fee per form to support the

costs of collecting and evaluating the data. Upon joining the registry, each center must identify a cardiologist who will be the contact person for their institution. This is the only person to whom annual reports and other data will be released. In addition, each center identifies a data collector who is responsible for the timely submission of data to the PCCC. This person completes a paper form for each catheterization, surgery or death that occurs and attaches appropriate procedure reports for each. The form requests a minimal amount of data such as the date of the procedure; patient details such as age and weight; and information such as associated noncardiac conditions and previous operative procedures. These forms are then forwarded to the PCCC's central office for coding and entry into the PCCC database.

B. Individual registry form. All individuals are assigned a PCCC study code number. The information collected on each patient is listed in Table 1. The information collected is forwarded to the PCCC along with a copy of the catheterization, operative, autopsy, or death report. Trained coders review the reports and extract information, and code the cardiac diagnoses and types of operations. However, additional data such as exposures of interest (cardiopulmonary bypass time, circulatory arrest time, thymectomy, duration of radiation exposure during catheterization procedures), hemodynamic findings at cardiac catheterization, description of operation and of devices used (pacemaker, prosthetic valve and conduit types and sizes) can be extracted from the original paper PCCC forms. These forms have been digitized in PDF format and archive in a searchable, password protected webpage.

able 1. Data Collected in PCCC
atient Identifier
atient country and state of origin, or country of origin
ospital name
ncounter identification number
irth date
irth weight
ospital admission data
/eight at time of admission
revious cardiac operations (types and dates)
resence and type of noncardiac malformations or conditions
ardiac catheterization data, including date, weight and diagnoses
ardiac operation data, including date, weight, cardiac diagnosis and type of procedure
ischarge, transfer, or death date, including diagnoses at death.

C. Diagnoses. Each patient is classified under a single primary diagnostic code with additional diagnoses being considered as secondary. A diagnostic and operative classification was necessary for both common and rare conditions and operations.

D. Audits/Checks/Balances/Security. Each year the PCCC contacts the medical records at each participating center to independently ascertain the number of catheterizations, cardiac operations, and cardiac deaths for the year for individuals within that center ages 0-18. If discrepancies exist between the number of cases reported to the PCCC and the number in medical records, these discrepancies are resolved before the data from the center are analyzed. HIPAA best practices are followed.

Literature

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