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A multi-center cardiac registry. A method to assess outcome of catheterization intervention or surgery

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Abstract

This report describes a multi-institutional study of outcomes of pediatric-aged patients undergoing cardiac catheterization and cardiac operation. The data collected and analysis systems including adjustment for case-mix are described.

The data are used by individual centers to assess the nature and quality of their services as well as to contribute to the literature. Because of the large number of patients (63,181) on whom we have data, the Pediatric Cardiac Care Consortium has the ability to address important clinical problems presented by various cardiac anomalies or patient groups.

Keywords: Cardiac surgery; Outcome analysis; Interventional cardiac catheterization

This paper describes the Pediatric Cardiac Care Consortium (PCCC). Initially developed 20 years ago by the voluntary participation of five hospitals in the Upper Midwest, the PCCC has expanded to include more than 35 pediatric cardiac surgical centers in North America. The goal of the program has been to improve cardiac care by analyzing catheterization and operative data from the participating centers and providing each center detailed comparison to the combined data. When reviewing the data, each center can identify areas where care and outcomes might be improved. Changes in the pattern of care can be tracked, and outcomes can be assessed in a non-punative environment [1,2].

1. Origin and development of program

Between 1953 and 1976, the federal Department of Maternal and Child Health funded a Minnesota-based Regional Cardiac Program intended to provide financial support for medical care to families of children with congenital heart disease from the states surrounding Minnesota. Of the 10 original federally-funded regional cardiac programs, by the early 1970s, the Minnesota program was one of only two remaining, the other being located at Johns Hopkins Hospital. Because of the availability of both public and private funding for health care, the regional director of Maternal and Child Health (John Dyer, MD) challenged pediatric cardiologists in the Upper Midwest to reexamine the use of these federal funds. Pediatric cardiologists from the Mayo Clinic and the Universities of Iowa and Minnesota met with their state directors of Maternal and Child Health. From these discussions, a non-profit organization, Northern Great Plains Regional Cardiac Program (NGPRCP), was formed that would receive these federal funds. The initial purpose of the NGPRCP was to collect and analyze data on children with cardiac anomalies undergoing cardiac catheterization or surgery, to provide education to families with a child with congenital heart disease, and to work toward regionalization of cardiac care.

The initial participating centers in NGPRCP which provided the majority of cardiac care in the great plains states were the Mayo Clinic, Minneapolis Children's

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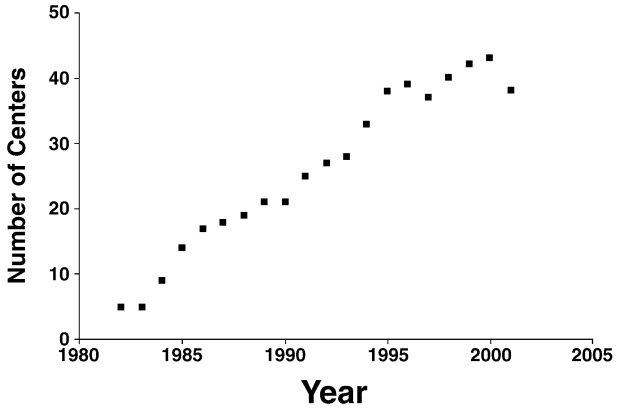

Fig. 1. Graph showing number of participating centers per year. Number of centers increased from initial five centers to current 38 partipants.

Medical Center, the University of Iowa, the University of Nebraska and the University of Minnesota. After the first years, the program concentrated on data collection and analysis in an effort to improve outcome and quality of cardiac care for children in the Upper Midwest.

Since its inception, the program collected and analyzed information on patient demographics, cardiac catheterization, electrophysiologic studies, cardiac operations and deaths of children with cardiac anomalies at the participating centers.

In the two subsequent decades, other centers from the United States and Canada have voluntarily joined the registry (Fig. 1). For some centers, joining the program was motivated by the 1989 guidelines of the Joint Commission on the Accreditation of Hospitals which added a focus on analysis of outcomes of care and encouraged hospitals to participate in quality assurance programs.

In 1990, faced with losing our federal funding, the name of the program was changed to Pediatric Cardiac Care Consortium to reflect that the program was not focused solely on the Upper Midwest [3]. Subsequently we have been self-supporting from volume-based fees paid by individual cardiac centers.

2. Program considerations and principles

In forming the data registry, we recognized that the incidence of congenital heart disease (8/1000) and that indeed cardiac problems in children was low. Thus, collaboration between centers was necessary to have sufficient numbers of patients to conduct meaningful outcomes analysis and comparisons.

Furthermore, we focused on only two major outcomes, death and length of hospital stay. We have used the latter as a surrogate for morbidity since the gathering of data on morbidity is costly, often involving chart audits. Additionally, there are difficulties in defining and quantifying specific morbidities.

Confidentiality of both the cardiac center and individual patient was mandatory. Center-specific data and reports are available only to the particular center and are unavailable to other centers. The PCCC does not receive the names of patients. Names are removed from catheterization, operative and autopsy reports before submission for analysis. Our study has been accepted by the Institutional Review Board (IRB) of the University of Minnesota and found to be Health Insurance Portability and Accountability Act (HIPAA) compliant.

To assure the prompt transmission of data to the PCCC office, we minimize the time required by pediatric cardiologists and cardiac surgeons at a center to complete or code forms. Our system uses secretarial or other ancillary assistance to gather and forward the data to us for completion and analysis. All coding of data is done centrally by trained coders. In this way, we achieve uniform coding and expedite entry of information into our database.

3. Goals of the program

The goals of the program have been to create a network of centers providing care to children with cardiac anomalies. Through this network, data can be collected and collated to accomplish the following:

1. Development of a centralized data acquisition and analysis method.
2. Creation of a uniform diagnostic and procedure coding and classification system.
3. Creation of methods for analysis and comparison of outcomes.
4. Development and application of statistical methods to adjust outcomes to reflect differences in patient populations cared for at the individual cardiac centers.

4. Patient data

The patient population studied includes all individuals under age 21 years who undergo cardiac catheterization, including interventional and electrophysiologic, or cardiac operation or who die of a cardiac malformation in a participating hospital. Hospitals may electively report adults who have congenital heart disease. We do not collect data on premature infants undergoing treatment of patent ductus arteriosus.

Information in six categories is collected on each patient:

1. Patient demographics: county, state and country of residence, birth date and birth weight for patients <366 days of age.
2. Hospitalization data: hospital name, admission date, admission weight.