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Use of an Administrative Database to Determine Clinical Management and Outcomes in Congenital Heart Disease

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Abstract

We review our 16-year experience using the large, multi-institutional database of the University HealthSystem Consortium to study management and outcomes in congenital heart surgery for hypoplastic left heart syndrome, transposition of the great arteries, and neonatal coarctation. The advantages, limitations, and use of administrative databases by others to study congenital heart surgery are reviewed.

Keywords

aorta/aortic; congenital heart disease (CHD); congenital heart surgery; database (all types)

In the late 1980s and early 1990s, there was considerable debate over the optimal management of neonates with hypoplastic left heart syndrome (HLHS). National cardiology conferences often included a symposium on the subject with speakers advocating the Norwood procedure, cardiac transplantation, or palliative care, frequently followed by asking the audience “What do you recommend for your patients?” or “What if it were your child?” As we considered this issue within our own institution, we sought to have a better understanding of management practices across the country and the outcomes for the two surgical options. We elected to study this issue through the use of a large discharge database to which we had access, that of the University Hospital Consortium (UHC), subsequently renamed the University HealthSystem Consortium.[1]

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In the same era, another clinical issue was management of neonates with transposition of the great arteries (TGA). Atrial switch procedures had been practiced for over 25 years, but in the mid- and late-1980s many institutions began performing the more challenging arterial switch procedure. Again, we sought to determine how frequently the arterial switch operation was employed and the resultant mortality rate.[2] We have subsequently used the UHC discharge database to study management of neonates with coarctation,[3] the influence of congenital heart disease (CHD) on mortality for noncardiac surgery,[4] and to update nationwide experience with HLHS.[5,6]

The purpose of the present review is to summarize our 16-year experience using this large, multi-institutional database to study the management and outcomes of children with CHD.

Description of the Database

The University HealthSystem Consortium, based in Oak Brook, Illinois, and formed in 1984, is an alliance of 107 academic medical centers and 246 affiliated hospitals which comprise about 90% of the nonprofit academic medical centers in the United States. Membership does not, in general, include private, free-standing children's hospitals. The mission of the UHC is to "create knowledge, foster collaboration, and promote change to help members succeed." Products and services provided by UHC include comparative data in clinical, operational, faculty practice, financial, patient safety, and supply chain areas. Information sharing is a key to the success of the UHC and member organizations, which routinely share data to improve quality and operations. One of the most powerful tools provided by the UHC is a patient-level clinical database that contains administrative data on all inpatient hospital discharges for most member organizations. This Clinical Database/ Resource Manager (CDB/RM), which served as the basis for the research studies described in this article, contains patient demographics, utilization patterns, diagnostic and procedure codes, outcomes (mortality and readmissions) financial data including charges and costs (estimated from the cost-to-charge ratio); risk adjustment is also provided, using logistic regression analysis and other statistical methods. The consortium uses the diagnosis and procedure codes of the *International Classification of Diseases, Ninth Revision, Clinical Modification* (*ICD-9-CM*).

Multiple procedures are in place to ensure accuracy of data. Data passed through a "rules engine" with over 200 data quality rules to determine suitability for inclusion. Quarterly coding profile reports are generated which compare the frequency of various measures and conditions with previous reporting periods and with peers. Benchmarking projects target particular diagnosis and procedure codes to determine the accuracy of documentation and coding.

Membership in the consortium has increased considerably during the period during which we have used it. At the time of our first analysis of management of HLHS in 1995,[1] we had data on 636 neonates from 40 member institutions, whereas our most recent analysis[6] included data from over 3500 neonates from 118 institutions, 41 of which reported performing Norwood or Sano procedures.

Summary of Studies Using the UHC Database

The data regarding neonates admitted with TGA showed that by the late-1980s and early-1900s the arterial switch operation had largely replaced the atrial switch operations as initial management of TGA.[2] It also demonstrated that surgical results obtained in multiple centers across the country were not as good as that reported in single-institution studies from select, large-volume institutions. Despite reports[7,8] of mortality rates as low as 5.5% to 9.4%, mortality was 14.8%among the institutions in the UHC.

Our first analysis of the UHC database to determine the management and outcome of HLHS revealed that from 1989 to 1993, 15% of 636 neonates with HLHS were discharged to home without surgical intervention.[1] Mortality for the Norwood procedure was 53%. The second analysis,[5] encompassing the entire decade of the 1990s, showed that 10% of neonates with HLHS were discharged without surgery and that mortality had fallen to 42% among 1203 neonates undergoing first-stage palliation. This analysis also showed that lower mortality rates were generally, but not exclusively, achieved by institutions performing a larger number of procedures. Our most recent analysis[6] of HLHS data showed that mortality for first-stage palliation fell from 43% in 1998 to 18% in 2007, while mortality for the second and third stages (Glenn and Fontan) remained fairly constant at 4% to 5%.

The impact of cardiovascular disease on mortality for noncardiac surgery has been well studied in adults, but there is little information on the effect of CHD on mortality for noncardiac surgery in children. We used the UHC database to study the influence of CHD in 191,261 patients undergoing noncardiac surgery in the mid-1990s.[4] A diagnosis of CHD was associated with increased mortality risk of both minor and major procedures and was greatest in neonates and infants where the presence of CHD was associated with a 2-fold increase in mortality for noncardiac surgery.

An analysis of 1516 neonates with coarctation of the aorta provided insight into the associated lesions, initial management, and outcome with data from 57 institutions.[3] Over half of the patients had an intracardiac shunt and aortic or mitral valve abnormalities were present in about a quarter. Mortality was 5.7% in the 1045 infants who underwent operation. Only 25% of patients with ventricular septal defect, endocardial cushion defect, or double outlet right ventricle had intracardiac repair of the shunt lesion during the initial hospital admission. In the mid-1990s, 21% of neonates with simple coarctation underwent cardiac catheterization prior to surgery.

Discussion

The major advantage of use of this large, multi-institutional database has been the ability to study management and outcomes of congenital cardiac defects across a broad spectrum of institutions across the country. Individual patients are nonselected and the results are free of any bias toward publication of favorable results. We were able to determine management practices such as how many infants with HLHS were discharged without surgical intervention and whether cardiac catheterization was routinely performed before surgery, data which might have required expensive surveys.

Research databases have been used to study the management and outcome of CHD for over 20 years,[9] and several new research databases have recently emerged or are under development.[10] There have been a modest number of studies using administrative databases with discharge data similar to that available from the UHC. Chang and colleagues have used the California discharge database to study risk factors for mortality following congenital heart surgery[11–13] and factors influencing age at operation.[14] Discharge data are available from several states (generally Medicaid data) and have been used to study the relationship of surgical volume to surgical mortality,[15,16] racial and ethnic effects on mortality,[17] and the effect of insurance by Medicaid on surgical mortality.[18]

Among the largest available administrative databases are the Kids' Inpatient Database (KID) which was developed as part of the Healthcare Cost and Utilization Project of the Agency for Healthcare Research and Quality and the Nationwide Inpatient Sample of the Healthcare Cost and Utilization Project (NIS). The 2006 KID data set includes inpatient data on patients 20 years of age and younger from 3739 hospitals extracted from 38 state inpatient databases. Earlier versions of the database have been used to determine racial and ethnic effects on mortality for congenital heart surgery and resource utilization for these procedures.[19,20] The NIS database has been used to compare mortality rates for pediatric cardiac surgery from an administrative database with that derived from contemporary clinical databases.[21]

Compared to studies using research databases, administrative databases are quite economical, both in terms of finances and time. The data in the UHC database is routinely collected and transmitted to the central office for multiple other uses. Data entry does not require the time or expertise of the clinical health care staff.

There are, however, significant limitations in the use of an administrative database to answer clinical questions.[21–26] Many hospitals use the *ICD-9* codes, which are not as current nor as detailed as coding specifically designed to describe procedures for CHD. In particular, there are no *ICD-9* procedure codes for many complex congenital heart operations, especially those generally condensed as eponyms (eg, Ross procedure, Mustard procedure). There is no *ICD-9* code for either the Norwood or Sano procedure, and we were forced to assume that these were performed on the basis of codes for cardiopulmonary bypass, creation of atrial septal defect, and systemic-pulmonary shunt in a neonate with the code for HLHS. Intent to treat is also difficult to determine; many infants with HLHS died without surgery, but frequently it could not be determined whether they were receiving comfort care or whether they died despite aggressive medical management. Discharge databases typically do not allow follow-up of individual patients over time and thus survival curves cannot be generated. Finally, although all databases are subject to coding errors, these are probably more frequent in administrative databases than in research databases with data entry by clinical staff. Some errors are fairly obvious, for example, an infant with a diagnosis of HLHS who underwent surgical repair of tetralogy of Fallot, but others are more difficult to detect.

Databases[24–26] using *ICD-9* diagnostic codes to identify cases of CHD have been shown to have a sensitivity of only 60% to 85% and relatively poor specificity.

Better results have been obtained using specific *ICD-9* procedure codes. For example, Welke et al[21] found statistically similar mortality rates for 5 of 6 severity categories of congenital heart operations when comparing NIS administrative data to that of the clinical database of the Society of Thoracic Surgeons. We have attempted to eliminate some potential errors by collecting both diagnostic codes and procedure codes and by examining discrete outcomes (eg, discharge status: discharged, transferred, or expired). Welke et al[21] provide a detailed discussion on the uses and limitations of both administrative and clinical databases for studying mortality data in CHD.

As long as the limitations are realized, large multi-institutional databases provide an efficient and inexpensive resource for studying management and outcomes of congenital cardiac defects. They allow study of very large and unselected numbers of patients from across the country and may be more representative of general practice than single-institution or research-based reports.

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Abbreviations and Acronyms

CDB/RM	Clinical Database/Resource Manager
CHD	congenital heart disease
HLHS	hypoplastic left heart syndrome
ICD-9-CM	*International Classification of Diseases, Ninth Revision, Clinical Modification*
KID	Kids' Inpatient Database
NIS	Nationwide Inpatient Sample of the Healthcare Cost and Utilization Project
TGA	transposition of the great arteries
UHC	University Hospital Consortium

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