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Original Article

Databases for assessing the outcomes of the treatment of patients with congenital and paediatric cardiac disease – a comparison of administrative and clinical data

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Abstract The introduction of the reporting of medical and surgical outcomes to the public and the potential implementation of initiatives involving pay-for-performance have invigorated debates about the relative benefits of administrative and clinical databases for comparing rates of mortality at the level of the hospital and surgeon. While general agreement exists that public performance report cards must use the highest quality data available, debate continues regarding whether administrative or clinical data should be utilized for this purpose. Clinical databases may contain information more relevant to risk-adjustment, but the currently available clinical databases are voluntary and suffer from validity concerns. Administrative data, however, suffer from inaccuracies of coding and a lack of potentially informative covariates. Particularly problematic to congenital heart surgery is the non-uniform application of coding algorithms to define complex reconstructive procedures for which there is no unique code assignment. The purposes of this manuscript are; therefore, to discuss the relative advantages and limitations of both clinical and administrative data, and to provide a brief introduction to currently available databases germane to the study of congenital cardiac disease.

Keywords: Congenital heart disease; outcomes; paediatric; surgery

THE INTRODUCTION OF THE REPORTING OF MEDICAL and surgical outcomes to the public and the potential implementation of initiatives involving pay-for-performance have invigorated debates about the relative benefits of administrative and clinical databases for comparing rates of mortality at the level of the hospital and surgeon. The purposes of this manuscript are to discuss the relative advantages and limitations of both clinical and administrative data, and to provide a brief introduction to currently available databases germane to the study of congenital cardiac disease.

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Administrative data

In the United States of America, administrative databases were designed for the collection of data about claims and billing. Subsequently, governmental agencies and insurance companies used these data for calculating publicly reported surgical rates of mortality and for profiling of providers. In the United States, two administrative databases have applicability to congenital cardiac surgery:

- Nationwide Inpatient Sample, commonly called the NIS[1]
- Kids' Inpatient Database, commonly called the KID.[2]

Both are derived from discharge abstracts collected at the level of the state and then sampled at the federal level.

Nearly all administrative databases in the United States are derived from the Uniform Hospital Discharge Data Set (UHDDS). Formulated in 1972, the Uniform Hospital Discharge Data Set is a uniform, minimum dataset that allows investigation of cost and quality of short-term hospital services across regional and national populations. The format in current use is the 1992 Uniform Bill, named UB-92. Each record represents a stay in an inpatient facility by a beneficiary and contains data from the UB-92 hospital discharge abstract. The data in the record include:

- Visit identifier
- Demographics, including age, gender, race, and ethnicity
- Zip code, county, and state of residence
- Hospital identifier
- Dates of admission, discharge, and death for patients who died during the visit
- Diagnoses Codes from the International Classification of Diseases, Ninth Revision, Clinical Modification, with 1 primary diagnosis and up to 9 secondary diagnoses
- Procedure Codes from the International Classification of Diseases, Ninth Revision, Clinical Modification, with 1 primary procedure and up to 5 secondary procedures
- Priority of admission (emergent, urgent, or elective)
- Source of admission, such as emergency room or transfer
- Vital status at discharge (alive or dead)
- Location of discharge, such as home, acute care hospital, or skilled care facility.

Although designed for billing, administrative databases have been used extensively in research related to health services.[3–5] They are relatively inexpensive, readily available, and include large groups of patients from state or national areas. In addition, they are often available for a number of years, facilitating longitudinal studies. Due to their large size, these databases can generate sample sizes often not available in single or even multi-institutional databases. This large volume of data is especially helpful for the study of rare diagnoses and procedures. The large size of administrative databases also may mitigate, in part, coding inaccuracies. The detail of administrative coding allows one to investigate some specifics of the clinical status of the patients. Since they were designed for billing purposes, administrative databases excel as sources of financial data not available from other sources.[5] Additionally, derivation of accurate data regarding procedures is facilitated by the use of administrative data because the current healthcare system provides procedural-based remuneration.

Administrative databases are inclusive by design. They either include all hospitals within a specified geographic area, such as state-level databases, or utilize a stratified sampling design that allows a fixed percentage of hospitals to accurately represent the entire sampling universe. Therefore, findings from within the sample can be generalized to the larger population from which the sample was selected. Such sampling structures also have a statistical advantage in that they can be used within the context of hierarchical mixed models, which account for both random and fixed effects.[6] By including information from both high and low performing and high and low volume hospitals, administrative data can be used to evaluate the practice of hospitals that are less likely to participate in voluntary, clinical databases. The higher average mortality rates seen in administrative databases reflect this difference in populations (Fig. 1). Inclusiveness also provides a unique opportunity to study trends and patterns among regional or national geographic areas. This characteristic is particularly desirable for a dynamic specialty like congenital cardiac surgery, in which novel therapeutic techniques are rapidly developed at index centres and variably disseminated to other peripheral centres.

Despite these advantages, administrative data have important limitations.[7] Many of these are a result of the documentation of the clinical status of the patients using codes from the International Classification of Diseases, Ninth Revision, Clinical Modification. While in general, these codes from the International Classification of Diseases capture a great amount of detail about diagnoses and procedures, multiple areas exist where the codes are nonexistent or lack the desired granularity.[8,9] For example, there is no procedure code for the Norwood operation. In order to select Norwood operations from an administrative database, one must construct a composite coding algorithm that contains individual procedural elements encompassing the Norwood operation. Similar problems can be expected as other technically complex operations become more common, such as the following operations:

- The Yasui operation, which involves a Rastelli operation and a "Norwood type arch reconstruction", in other words, a conduit insertion from the right ventricle to pulmonary artery and an intraventricular tunnel of the left ventricle to the neoaorta along with a reconstruction of the aortic arch
- The Nikaidoh procedure, which involves aortic root translocation over the left ventricle
- The REV procedure, or "Reparation l'etage Ventriculaire", which involves conal septal resection and creation of a left ventricle to aorta intraventricular tunnel along with a right ventricle to pulmonary artery direct anastomosis.

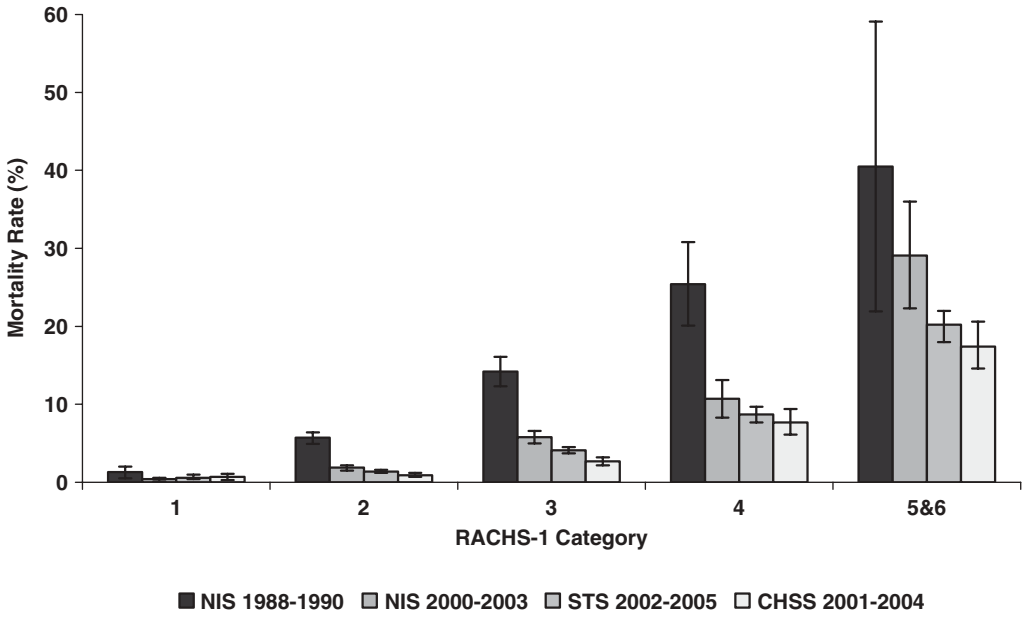

Figure 1.
Paediatric cardiac surgical mortality rates from administrative and clinical databases. CHSS = Congenital Heart Surgeons Society,[22] NIS = Nationwide Inpatient Sample,[1] RACHS-1 = Risk Adjustment for Congenital Heart Surgery, Version 1,[23] STS = Society of Thoracic Surgeons.[24]

In addition, diagnostic codes from the International Classification of Diseases, Ninth Revision, Clinical Modification do not capture many findings from physical examination, diagnostic findings, laboratory values, and haemodynamic measurements that have prognostic value and importance in risk models.

The complex case-mix of paediatric cardiac surgery and the structure of the collection of administrative data lead to considerable variation in the quality of administrative data.[10,11] The administrative coding personnel that obtain the UB-92 data from abstraction of the chart are skilled in coding, but, they are not clinicians and they have no contact with the clinical team or the patient; their abstractions are derived solely from what is explicitly stated in the medical record. Variation in the quality of administrative data may also result in part from the agenda for coding being financially driven. A greater impact likely comes from a combination the following factors:

- Coders' limited knowledge of paediatric cardiac surgery
- Coders' restricted ability to clarify conflicts in the data and fill in missing data
- Poor or inconsistent documentation in the medical record.[12]

In addition, since procedures in similar categories may be performed in both the operating room and the cardiac catheterization laboratory, miscoding of interventional procedures as surgical procedures occurs.

The algorithm of coding used in administrative data is further restricted by the date-stamp limitation.[5] The date-stamp limitation refers to the fact that diagnostic codes do not differentiate between pre-existing diagnoses, in other words problems present at admission to the hospital, and conditions that developed during the hospitalization, potentially as complications of the care delivered. The misidentification of postoperative complications as comorbidities may lead to falsely elevated discriminatory power, bias assessment of the performance of institutions or providers toward more favourable outcomes, and preclude the discovery of influential determinants.

The limited number of diagnostic and procedural codes recorded may prevent the listing of important secondary diagnoses and procedures, especially within the context of a lengthy hospitalization. Further, beyond primary diagnosis and procedure, the diagnoses and procedures included may not be accurately ordered within a structured hierarchical domain of decreasing clinical importance. This weakness may lead to erroneous conclusions. For example, diabetes may appear protective since it is recorded for patients who have a small number of diagnoses, but is supplanted by other diagnoses in patients who have a large number of diagnoses.[13]

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Clinical data

Clinical databases are maintained by several groups:

- Professional organizations, such as The Society of Thoracic Surgeons, The European Association for Cardio-Thoracic Surgery, and the Pediatric Cardiac Care Consortium
- States, such as the New York Cardiac Surgery Reporting System
- Hospitals
- Private groups.

Clinical data are collected by clinical personnel, who have a better knowledge of cardiac surgery than administrative coding personnel. In circumstances where they are not intimately involved in the process of care of the patient, they can identify where preoperative patient-level comorbidities are recorded, review the operative notes for surgical data, and follow the patient daily to track complications. As a result, clinical data may be more accurate than administrative data; however, they too suffer from a limited number of elements of data, inaccuracies of coding, and the lack of long-term follow up. The close association between those who collect the data and those invested in how the data are used has led to the presumption that physicians and healthcare providers will game the system through the data collection process. This concern has increased with the implementation of reporting of medical and surgical outcomes to the public and governmental pay-for-participation programs, along with the potential implementation of initiatives involving pay-for-performance, and has led some to question the validity of clinical data.

Participation in most clinical databases is voluntary, which creates biases regarding outcomes. Smaller hospitals, hospitals with limited resources, and those with lower performance may abstain from participation. As a consequence, the representative nature of clinical databases is limited; results obtained may be more favourable than those achieved by the overall population of hospitals. In particular, hospitals which are interested enough to participate in a clinical database differ from non-participating hospitals in that they must at least have the infrastructure in place to collect the data. Participation may be a marker for further differences in structure and process including additional quality improvement initiatives.

Comparison of administrative and clinical data

While coding errors are widely perceived to be mainly a drawback of administrative data rather than clinical data, such a perception is oversimplified and potentially dangerous, as both are likely to contain some level of inaccuracy. Williams and McCrindle elucidated the characteristics of an academic database and argued that these data should be regarded as a gold-standard against which other sources of data ought to be judged.[14,15] Gallivan and colleagues deliberately seeded an established clinical database of congenital cardiac surgery maintained in Toronto, Ontario, Canada, named the Toronto Cardiovascular Surgery Database for Congenital Heart Surgery, with three types of errors at known rates between 0–20%:

- Errors of omission of data
- Errors of miscoding of outcomes such as alive or dead
- Miscoding of procedures.[16]

Expectedly, random errors had little effect, but rates of mortality calculated from the seeded database and the pristine database were sensitive to even small levels of miscoding of procedures and outcomes. The impact of these coding errors varies depending on the focus of the investigation. If coding errors are random within the population, their impact is diminished by the large sample sizes available with administrative, and to a certain extent, clinical data. The result of such random miscoding would be to bias the results of an analysis towards the null. However, in a small subset of the data, potential errors may not be randomly distributed and may confound the findings. When studying operations, errors from miscoded data can be reduced by including records where the procedural code matches to a plausible diagnostic code. For example, a patient would have to have both the diagnosis of tetralogy of Fallot and undergo the procedure of repair of tetralogy of Fallot to be included in a cohort. Using this same strategy, one could also reduce the number of patients with associated lesions, such as atrioventricular septal defect with tetralogy of Fallot, from being included in studies of isolated lesions.

Another limitation shared by both administrative and clinical databases is the short time-interval over which data from each patient is collected. In evaluating outcomes, both types of databases have used early death in an attempt to simplify and standardize analyses.[17] However, "early" is arbitrary and variously defined:

- Operative mortality, "defined as any death, regardless of cause occurring (1) within 30 days after surgery in or out of the hospital, and (2) after 30 days during the same hospitalization subsequent to the operation";[17] in other words, all deaths within 30 days of an operation and all deaths prior to discharge from the hospital
- In-hospital mortality, defined as death occurring after operation and during the same hospital admission as that operation

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- 30-day mortality, defined as death occurring within 30 days of operation regardless of hospital status.

None of these definitions recognize that the risk of death after an operation changes over time. Typically the risk is high at the time of operation but falls rapidly to a lower risk that is constant but not zero and much later, the risk rises in a third phase. Risk factors that influence outcome, either positively or negatively, in one phase may or may not affect outcome in any of the other phases. The early hazard phase of risk is unaffected by either the first 30-day period after operation or by hospital discharge. The report of The Congenital Heart Surgeons Society of outcomes in 710 neonates after the Norwood operation, for example, documented an early phase mortality that persisted beyond both discharge from the hospital and the 30-day definition.[18] These problems notwithstanding, clinical inferences drawn from both clinical and administrative data are severely limited by the short follow-up interval. Although the focus of most congenital cardiac surgical studies has been survival, the dramatic reduction in short term rates of mortality has refocused attention on longer-term outcomes including metrics of quality of life, which cannot be measured, quantified, or even inferred using current administrative nor clinical data.

While assessment of both long-term neurodevelopmental and health-related quality of life outcomes are important, another crucial determinant of the success, or failure, of a particular index treatment requires investigation of longitudinal outcomes *within the same patient*. The structure of both currently available clinical and administrative databases; however, precludes longitudinal assessment of individual patient outcomes, since the unit of measure is either a hospital discharge, as seen in the Nationwide Inpatient Sample and the Kids' Inpatient Database, or an operation, as in the databases of The Society of Thoracic Surgeons and The European Association for Cardio-Thoracic Surgery. In recent analyses, the databases of The Society of Thoracic Surgeons and The European Association for Cardio-Thoracic Surgery have used both operations and patient-admissions as the unit of measure. Related to this topic, is the potential redundancy of patient records. In both types of databases, depending on the chosen unit of analysis, the same patient may be counted multiple times with each discharge or operation, necessitating statistical correction, or at least awareness, of increased correlation among units of discharge or operation.

A different drawback of both clinical and administrative databases stems from, ironically, the large sample sizes often present. Analyses of large samples may produce statistically significant differences between either clinical risk-factors or treatment groups despite small actual or meaningful differences. It is therefore incumbent on clinicians, personnel engaged in research, and readers to be thoughtful of the true magnitude of the differences and whether or not these differences have clinical value or utility.

Formal investigations of the agreement between administrative and clinical data have found varying degrees of agreement between the two sources.[19] Parker and colleagues showed that a clinical risk-model for outcomes following coronary arterial bypass graft (CABG) operation has slightly better discrimination, with a C-index of 0.824, than an administrative model derived from a California state database, with a C-index of 0.799, but that the administrative model was robust to missing or omitted data.[4] Hannan and colleagues showed that risk-models derived from administrative data performed less well, with a C-index 0.78 that reduced to 0.73 after removal of miscoding complications as comorbidities; but importantly, they also found that the addition of a limited number of clinical variables to the administrative dataset nearly obviated the difference between models derived from both sources.[3] Similarly, Ugolini and colleagues compared risk models between the European System for Cardiac Operative Risk Evaluation, commonly known as EuroSCORE, and an administrative dataset, and found that linking hospital data across multiple episodes of care up to 1 year prior to coronary arterial bypass graft surgery for the same patient significantly improved the predictive capacity of an administrative-derived risk-model.[20]

Specific administrative databases relevant for congenital cardiac surgery

Nationwide Inpatient Sample

The Nationwide Inpatient Sample, commonly known as NIS, is the largest all-payer inpatient care database in the United States.[1] The Nationwide Inpatient Sample is managed under the Healthcare Cost and Utilization Project of the Agency for Healthcare Research and Quality. *The database is a stratified, cross-sectional sample that includes approximately 20% of all community (non-federal) hospital discharges in the United States. The sampling protocol is such that when a hospital is chosen, all discharges from that hospital for the selected time period are included.* Data from the Nationwide Inpatient Sample are available from 1988 to 2006, over which time, the number of states participating in the Nationwide Inpatient Sample has grown from 8 to 38. In 2006, the database contained discharge data on approximately 8 million hospital stays at 1045 hospitals in

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38 states. For the 2006 Nationwide Inpatient Sample, the sampling frame, that is those hospitals for which data are available to the Healthcare Cost and Utilization Project, comprises approximately 90 percent of all hospital discharges in the United States. To ensure the representative nature of the database, the Nationwide Inpatient Sample is stratified by geographical region, hospital bed size, teaching status, urban versus rural location, and hospital ownership. Sampling weights are provided so that cases in the Nationwide Inpatient Sample can be used to produce estimates of the entire national hospitalized population. The Nationwide Inpatient Sample does not follow patients after discharge or link multiple hospitalizations of the same patient.

Kids' Inpatient Database

The Kids' Inpatient Database, commonly known as KID, was specifically designed for research on issues related to the health of children in the United States.[2] Like the Nationwide Inpatient Sample, the large size and national scope of the Kids' Inpatient Database make it well suited for study of national trends in health care utilization, access, charges, quality, and outcomes. The Kids' Inpatient Database is the only all-payer inpatient care database for children in the United States. Kids' Inpatient Databases are available from 1997, 2000, 2003, and 2006. The scope of the database has increased from data on patients 18 years of age and younger in 22 states in 1997 to data on patients 20 years of age and younger in 38 states in 2006. Each year, the Kids' Inpatient Database includes 2 million to 3 million paediatric discharges sampled from 2500 to 4000 community hospitals as designated by the American Hospital Association. This designation includes general and specialty hospitals, but excludes Federal hospitals and hospital units that are part of other institutions. The Kids' Inpatient Database contains clinical and resource use information included in the UB-92 hospital discharge abstract. The sampling strategy for the Kids' Inpatient Database differs from that for the Nationwide Inpatient Sample. To ensure an accurate representation of each hospital's paediatric case-mix, the discharges are sorted by state, hospital, diagnosis related group (DRG), and a random number within each diagnosis related group. *Systematic random sampling is used to select 10 percent of uncomplicated in-hospital births and 80 percent of complicated in-hospital births and other pediatric cases from each hospital for which data are available.* As with the Nationwide Inpatient Sample, sampling weights are provided so that the Kids' Inpatient Database can be used to produce estimates of the national paediatric population. The Kids' Inpatient Database does not follow patients after discharge or link multiple hospitalizations of the same patient.

Specific clinical databases relevant for congenital cardiac surgery

Society of Thoracic Surgeons Congenital Heart Surgery Database

The Society of Thoracic Surgeons (STS) maintains a provider-led voluntary cardiac surgical clinical database as a means of supporting national quality improvement efforts. The number of cases submitted annually to the congenital database of The Society of Thoracic Surgeons has grown from 3,121 operations from 10 participants in calendar year 1998 to 19,007 operations from 57 participants for calendar year 2007. Database participants can be individual surgeons, independent surgeon groups, or groups in partnership with hospitals at which cardiac surgery is performed. Each record corresponds to a primary cardiac surgical procedure. Data elements include basic patient demographic information, detailed information on comorbidities and preoperative risk factors, diagnosis, type of operation, and outcomes including in-hospital mortality, 30-day mortality, major morbidity and postoperative length of stay. Details on data definitions and collection methods, as well as the annual Executive Summary from the Society of Thoracic Surgeons Congenital Heart Surgery Database Report, can be viewed online at http://www.sts.org. Participants in the congenital database of The Society of Thoracic Surgeons enter data using uniform definitions and certified systems of software. The majority of sites have personnel dedicated to the collection of data, local analysis, and annual harvesting for submission to the Duke Clinical Research Institute, the centre responsible for warehousing and analysis of the data in collaboration with The Society of Thoracic Surgeons. These personnel form an extensive national network of Data Managers. The interaction between data personnel from across the database of The Society of Thoracic Surgeons and the support provided by the team at the warehouse of the database of The Society of Thoracic Surgeons provide incentive to collect complete and accurately defined information for local feedback and analysis to improve clinical quality of care. Because of these factors, clinical data such as the data in the congenital database of The Society of Thoracic Surgeons may be more accurate than administrative databases in many areas. In addition, the database can be modified to support specific research and quality improvement initiatives. Due to the specificity of the collected data to paediatric cardiac surgery, more accurate risk adjustment is possible.

The congenital database of The Society of Thoracic Surgeons has limitations as well. Although collected elements of data may be more specific for congenital cardiac surgery than those in administrative data, more peripheral information that may impact a patient may be excluded. For example, the ultimate outcome for a patient who undergoes closure of a patent arterial duct may be more related to conditions not directly related to the operation, such as necrotizing enterocolitis, which may not be captured in the database of The Society of Thoracic Surgeons. The congenital database of The Society of Thoracic Surgeons also lacks data about physical examination, laboratory values, and haemodynamic measurements that may be important to risk stratification. The congenital database of The Society of Thoracic Surgeons also lacks many preoperative risk factors more prevalent in adults than children, such as chronic obstructive pulmonary disease, hyperlipidemia, hypertension, and smoking history. As a result, the risk stratification of adults with congenital cardiac disease may be less than ideal. Follow-up ends at 30 days after hospital discharge and does not include later information about the neurological or functional status of the patient. In addition, the elements of data tracking preoperative risk factors and complications were not fully defined until 2007, and efforts to verify the completeness and accuracy if the data are also quite recent.

The Society of Thoracic Surgeons also maintains a national cardiac surgical database for adults. Surgeons who primarily perform surgery on adults with acquired cardiac lesions typically submit data to this database. Congenital operations, however, may be entered as well. The adult database contains considerably more detail on risk factors that may be important to the outcomes of adult patients; however, it lacks the detailed congenital diagnostic and procedural information present in the congenital database of The Society of Thoracic Surgeons.

Pediatric Cardiac Care Consortium

The Pediatric Cardiac Care Consortium is a collaborative, voluntary effort of paediatric cardiologists and cardiac surgeons to gather and analyze data regarding operative results.[21] The Pediatric Cardiac Care Consortium, incorporated under the leadership of James H. Moller, MD at the University of Minnesota in 1982, currently has data from over 100,000 patients from 48 centres in North, Central, and South America. The Pediatric Cardiac Care Consortium collects information on each child who undergoes cardiac catheterization, electrophysiological study, or a cardiac operation, or dies with a cardiac malformation, at participating institutions. The data are analyzed annually and individual reports are created for each centre, allowing anonymous comparison among participating centres.

Adult congenital cardiac disease

The growing population of adults surviving with congenital cardiac disease has focused attention on the importance of describing time-related outcomes, especially with regards to how these individuals differ from their age-matched peers. Unfortunately, because this population has only recently become recognized, adults with congenital cardiac disease are treated by a variety of institutions and providers, and are not fully described in most databases. Although the Congenital Heart Surgery Database of The Society of Thoracic Surgeons contains detailed diagnostic and procedure information for congenital cardiac surgical patients regardless of age, it focuses on the paediatric population and does not contain comorbidities that are important in the risk adjustment of adult patients. This database also does not contain the detailed diagnostic and procedural information needed to describe concomitant acquired cardiac disease that these patients may have. The National Adult Cardiac Surgery Database of The Society of Thoracic Surgeons includes the comorbidity, diagnostic and procedural information relevant to acquired cardiac disease, but does not have detailed information regarding congenital cardiac disease. As a result, neither database is ideally suited for the adult congenital patient.

Adult congenital cardiac patients are not included in the Kids' Inpatient Database since the upper age limit of the Kids' Inpatient Database is 18 or 20 years of age, depending on the year of the sample. The Nationwide Inpatient Sample does include the population of adults with congenital cardiac disease, though the complexity and spectrum of congenital cardiac disease in adults, which includes patients with unrepaired, palliated, and completely repaired disease, poses a perhaps greater challenge to the limitations of administrative coding than the paediatric population. Strategies linking procedural codes with plausible diagnostic codes, as discussed previously, coupled with validation of data by comparison to institutional or academic databases, such as the data maintained by the Congenital Heart Surgeons' Society, may mitigate the influence of coding errors.

Conclusion

The increased interest of the public in healthcare outcomes has spurred interest in administrative databases and in the development of clinical databases. The distinctive advantages of each type

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of database make them suited for unique, but complimentary purposes. Both administrative and clinical databases suffer concerns about the validity of the data. Inattention to these concerns will result in the reporting of misleading information that will be used by governmental agencies, insurance companies, referring providers, and patients to make misinformed and potentially detrimental decisions about where to purchase, refer, or obtain healthcare. Ongoing efforts to improve the quality of the data and reconcile discrepancies between administrative and clinical data will be crucial to achieve thorough understanding and accurate reporting of congenital cardiac surgical performance. In order to address the outcomes important to patients and their families, cardiac surgical databases need to be broadened to include data about neurological and functional status, links to data from databases of cardiology, and long-term follow-up. The best description of the practice of congenital cardiac surgery will likely come from a combined approach that harnesses the strengths of both administrative and clinical data.

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