A Specific Health Information System for Adult Congenital Heart Disease Integrated with Electronic Health Records Can Facilitate Multicenter Research


Background and Objective

Adults with congenital heart disease (ACHD) are the fastest growing population in cardiology. Survey data show that most centers use an electronic health record (EHR) but not a similar tool for ACHD care (Figure 1).†

Objective: to determine if automated acquisition of existing electronic health records (EHR) in a common multicenter database can facilitate ACHD research by enabling analysis of patients across centers.

Methods

To profile a large ACHD cohort:
- Clinical information from existing EHRs at 5 ACHD centers (Figure 2) was integrated with CONGENERATE, an ACHD-specific clinical information system.
- Patients >18 years old with documented congenital defect seen by an ACHD provider in the last 10 years.
- Pre-defined demographic and clinical variables were collected.
- Billing (diagnosis) codes were used to identify anatomic defects.
- Patients stratified into mild, moderate, or severe disease.

Results

Data variables were those that existed in current EHR systems in discrete fields. The data exports consisted of demographic and diagnoses data that had been cross-mapped and imported into center specific installations of CONGENERATE for all patients >18 years old with at least one CHD-related office visit at one of the hospitals during July 2009 to June 2010.

Cross-mapping between EHR and CONGENERATE was complicated by multiple EHR systems and coding standards. CONGENERATE was built to accommodate international standards and multiple languages but issues that arose during integration of data included mapping diagnoses from centers that used different code sets.

Diagnoses that were cardiac-related were standardized by:
- EPCC Codes mapped to ICD-9:47
- ICD-9 to EPCC mapping was impractical due to the "one-to-many" relationship
- 2 sites used ICD-9 and 2 sites use EPCC

Each original diagnosis description was mapped to complexity then patients' highest complexity level was determined.1

| Diagnosis | ICD-9 | EPCC | CONGENERATE | CPT® | Core | International Classification of Diseases & Injuries, 9th Edition (ICD-9)
|---|---|---|---|---|---|
| Aortic Coarctation | 755.10 | 36.4 | CONGENERATE-9012 | 992.89 | CONGENERATE-9012 | CONGENERATE-9012
| Pulmonary Hypertension | 401.00 | 36.4 | CONGENERATE-9012 | 741.54 | CONGENERATE-9012 | CONGENERATE-9012

Conclusion

Data validation checks included reviewing all missing fields, as well as missing and maximum values. 10 patients were excluded from the analysis due to age < 18 years old. Initial analysis also revealed height and weight columns were switched for one site when BMI was calculated using height and weight variables.

30 patients' data were validated by physician chart review. Each investigator compared a short list of patients' data from a center's EHR system to the data entered in CONGENERATE and then provided in the data extract. One error was identified and corrected in the dataset in two patients at one center. (Height and weight variables were incorrectly entered in EHR).

Acknowledgements

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Disclosures

No authors have any disclosures relevant to this work.

Appendix

Table 1: Standard Coding Systems Used by Centers

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Definitions and Coding

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Conclusions

- First study to report the application of a tailored clinical research information system for ACHD.
- Automated acquisition of existing EHR data to a multicenter database can be achieved with accurate clinical information, whereas more uniformly in anatomical detail is required.
- The population sampled was predominantly female, Caucasian/non-Hispanic and nearly two-thirds of patients had moderate or severe congenital heart disease.
- Obesity prevalence was similar to published US averages.