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Congenital Cardiology Solutions

A SPECIFIC HEALTH INFORMATION SYSTEM FOR ADULT CONGENITAL HEART DISEASE INTEGRATED WITH ELECTRONIC HEALTH RECORDS CAN FACILITATE MULTICENTER RESEARCH

ACC Moderated Poster Contributions

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Background: Adults with congenital heart disease (ACHD) are the fastest growing population in cardiology. We pioneered a tailored clinical-research information system to foster multicenter data sharing. Our objective is to determine if automated acquisition of existing electronic health records (EHR) integrated with 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 current EHRs at 5 ACHD centers was integrated with CONGENERATE, an ACHD-specific health information system. Patients >17 years old with documented congenital heart defects seen by an ACHD provider were identified. Demographic and clinical variables were collected. Billing codes were used to identify anatomic defects and stratify patients into mild, moderate, or severe disease complexity. In 30 randomly selected patients, acquired data were validated by manual chart review.

Results: Data on 2,410 patients (62% female, age 37.4±13.7 years) were obtained. Mean BMI was 27.1± 6.3 kg/m², and 24.7% were classified as obese. Race/ethnicity representation was 4.7% African-American, 1.7% Asian, 0.3% native American, 5.5% other, 3.3% Hispanic, and 88% were Caucasian/non-Hispanic. 6.5% had no racial/ethnic identifier. Diagnoses were inadequate for complexity stratification in 32%. Of patients who could be stratified, 37% had mild, 39% moderate, and 24% severe congenital heart disease. Race designation was erroneous in one patient; no other errors or misclassifications were identified among the patients selected for manual review.

Conclusions: We report the application of a tailor-made clinical and research information system for ACHD. Automated acquisition of existing EHR to a multicenter database can be achieved with accurate demographic information, whereas more uniformity in anatomical detail is required. In this first harvest of data, the population sampled was predominantly female, Caucasian/non Hispanic, and nearly two-thirds of patients had moderate or severe congenital heart disease. Continuing efforts to refine the tool will potentiate multicenter registries and research.