




Adult congenital heart disease care in a municipal public health system

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Original Article

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Abstract

Specialty care is associated with improved outcomes for adults with adult CHD and must be extended to the underserved. A retrospective cohort study was performed to describe the provision of care to adult CHD patients in America's largest municipal public health system including patient demographics, diagnostic and therapeutic procedures, and adherence to guideline-recommended surveillance. We identified 229 adult CHD patients aged >18 years through electronic medical records. The most common diagnoses were atrial septal defect, ventricular septal defect, patent ductus arteriosus, and valvular pulmonary stenosis. In total, 65% had moderate or greater anatomic complexity. A large number of patients were uninsured (45%), non-white (96%), and non-English speaking (44%). One hundred forty-six patients (64%) presented with unrepaired primary defects. Fifty eight patients underwent primary repair during the study period; 48 of those repairs were surgical and 10 were transcatheter. Collaboration with an affiliated Comprehensive Care Center was utilised for 28% of patients. A high proportion of patients received adult CHD speciality visits (78%), echocardiograms (66%), and electrocardiograms (56%) at the guideline-recommended frequency throughout the study period. There was no significant difference in the rate of adherence to guideline-recommended surveillance based on insurance status, race/ethnicity, or primary language status. The proportion of patients who had guideline-recommended adult CHD visits, echocardiograms, and electrocardiograms was significantly lower for those with more advanced physiological stages. These results can inform the provision of adult CHD care in other public health system settings.

Adult CHD speciality care has been associated with improved outcomes and must be extended to the underserved.^{1,2} Previous studies have shown that socio-economic status and financial hardship can be associated with poorer outcomes in this population.^{3,4} Comprehensive adult CHD care requires significant resources, however, including frequent surveillance, advanced diagnostic testing like cardiac MRI, and invasive intervention including cardiac surgery.⁵ For the socio-economically disadvantaged, cost can be a major barrier to care.

New York City houses the largest public healthcare system in the United States, NYC Health + Hospitals Corporation, which served 1.4 million patients in 2012.⁶ Herein we describe the administration of adult CHD speciality care in NYC Health + Hospitals Corporation. Our aims were (1) to define the characteristics of the adult CHD population receiving services from this public system; (2) to describe the services received, including diagnostic and therapeutic procedures; and (3) to assess adherence to guideline-recommended surveillance, as defined by the American Heart Association/American College of Cardiology.

Materials and methods

The adult CHD Clinic at NYC Health + Hospitals/Bellevue, which is in session two half-days per week, receives referrals from throughout the NYC Health + Hospitals Corporation system. The clinic is currently staffed by two board-certified adult CHD physicians. Care is provided in the NYC Health + Hospitals/Bellevue system regardless of insurance status.

Study subjects were identified using an administrative database. Data from the electronic medical records of NYC Health + Hospitals/Bellevue as well as New York University Langone Health, an affiliated private academic hospital system housing an Adult Congenital Heart Association-accredited Comprehensive Care Center, were then collected. Individuals who had a “new visit” or a “revisit” in the Bellevue adult CHD clinic between January 2015 and March 2021 were screened for inclusion. Both in-person visits and tele-health visits were counted. Patients <18 years old at the beginning of the study period and patients with a non-adult CHD diagnosis were excluded. The institutional review boards of New York University Langone Health and

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NYC Health + Hospitals/Bellevue approved the study and informed consent was waived for this observational study.

Patients' race/ethnicity was determined by self-identification and primary language was obtained from the electronic medical record. Insurance status was determined at the most recent adult CHD visit. Those with multiple insurance coverage types were counted for each insurance plan they had.

Diagnostic tests were tallied including echocardiograms, electrocardiograms, and cardiac MRI examinations. Procedures tallied included cardiac surgeries, diagnostic and therapeutic catheterizations, electrophysiology studies, ablations, and implantable cardioverter defibrillator or pacemaker implantations. For patients seen in the NYC Health + Hospitals/Bellevue clinic, these healthcare services were tallied if they were administered either within the NYC Health + Hospitals Corporation or at the affiliated Comprehensive Care Center at New York University Langone Health.

Guideline-recommended surveillance was defined using the 2018 American Heart Association/American College of Cardiology Guideline for the Management of Adults with Congenital Heart Disease.⁷ The frequency of clinical visits, electrocardiograms, and echocardiograms was recorded for each patient, and guideline adherence was defined in a binary fashion as either adherent or non-adherent through the study period. Adherence to guideline-recommended care for each patient was evaluated starting at the point an individual established care in the Bellevue adult CHD clinic. Visits were classified as emergency department or inpatient hospitalisations based on the encounter type in the electronic health record. Usage rates of emergency department visits and hospitalisations were calculated with the number of events in the numerator and the number of person-years in the denominator. Descriptive statistics were used to describe population characteristics. Pearson chi-square tests were used to compare proportions.

Results

In total, 374 unique patients had a visit at the Bellevue adult CHD clinic during the study period, 229 of whom met inclusion criteria (Fig. 1). The majority of eligible subjects were female (62%); median age was 36.5 years (range 18–75). A total of 96% of patients identified as non-White and 56% of the population identified a language other than English as their primary language. Forty-eight percent were uninsured and 56% were insured with Medicaid, Medicare, private insurance, or dual coverage. Demographic data are shown in Table 1.

The most common diagnoses were atrial septal defect, ventricular septal defect, patent ductus arteriosus, and valvular pulmonary stenosis (Table 2). Based on American Heart Association/American College of Cardiology anatomic-physiologic classification, the majority were class II or III (moderate or great) anatomic complexity. At the time of the most recent visit, 62% were physiologic stages B, C, or D (Table 3). Nine patients (4%) had a resting oxyhaemoglobin saturation <92% and 24 (10%) had a diagnosis of pulmonary hypertension confirmed with right heart catheterization. Five patients (2%) had Eisenmenger syndrome. Arrhythmias and hypertension were the most common recorded comorbidities (Table 1).

Upon initial presentation to the Bellevue adult CHD speciality clinic, 146 patients (64%) had unrepaired primary defects. Patients with unrepaired defects were more likely to be uninsured (compared to insured: OR, 2.66; 95% CI, 1.5–4.7;

Table 1. Demographics of the study population

| Categories | Number | Percentage |
|-------------------------|--------|------------|
| Gender | | |
| Male | 87 | 38% |
| Age | | |
| 18–44 | 149 | 65% |
| 44–65 | 73 | 32% |
| 65+ | 7 | 3% |
| Race/Ethnicity | | |
| White | 9 | 4% |
| Black | 37 | 16% |
| Hispanic/Latino | 83 | 36% |
| Asian | 21 | 9% |
| Other | 79 | 34% |
| Primary language | | |
| English | 100 | 44% |
| Spanish | 109 | 48% |
| Mandarin | 8 | 3% |
| Other | 12 | 5% |
| Insurance* | | |
| Medicaid | 79 | 34% |
| Medicare | 9 | 4% |
| Private | 43 | 19% |
| No Insurance | 109 | 48% |
| Comorbidities | | |
| Hypertension | 56 | 24% |
| Heart Failure | 22 | 10% |
| Stroke | 2 | 0.9% |
| Coronary artery disease | 17 | 7% |
| Arrhythmias | 48 | 21% |
| Diabetes | 27 | 12% |
| Chronic kidney disease | 10 | 4% |

*Patients may have multiple insurance coverages so total percentiles will be >100%.

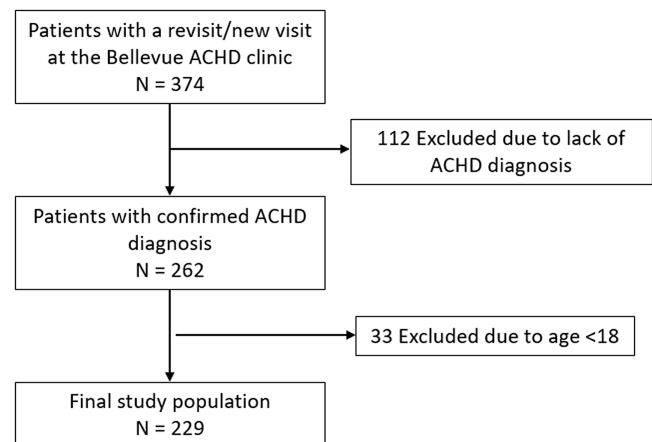


Figure 1. Derivation of study cohort. ACHD = adult CHD.

Table 2. Adult CHD diagnoses

| Diagnoses | Number | Percentage |
|---|--------|------------|
| Shunt Lesions | | |
| Atrial septal defect | 83 | 36% |
| Anomalous pulmonary venous connection | 11 | 5% |
| Ventricular septal defect | 30 | 13% |
| Atrioventricular septal defect | 2 | 0.9% |
| Patent ductus arteriosus | 24 | 10% |
| Left-sided obstructive lesions | | |
| Congenital mitral stenosis | 1 | 0.4% |
| Subaortic stenosis | 16 | 7% |
| Congenital valvular aortic stenosis | 7 | 3% |
| Supravalvular aortic stenosis | 1 | 0.4% |
| Coarctation of the aorta | 9 | 4% |
| Bicuspid aortic valve | 11 | 5% |
| Shone complex | 1 | 0.4% |
| Right-sided lesions | | |
| Valvular pulmonary stenosis | 23 | 10% |
| Double chamber right ventricle | 10 | 4% |
| Ebstein anomaly | 11 | 5% |
| Tetralogy of Fallot | 14 | 6% |
| Complex lesions | | |
| Transposition of the great arteries | 5 | 2% |
| Hypoplastic left heart syndrome | 1 | 0.4% |
| Tricuspid atresia | 2 | 0.9% |
| Pulmonary atresia | 3 | 1% |
| Double outlet right ventricle | 1 | 0.4% |
| Malformation or anomalies of the coronary vessels | 6 | 3% |
| Interrupted aortic arch | 1 | 0.4% |
| Endocardial cushion defect | 1 | 0.4% |
| Other defects | | |
| | 18 | 8% |

Patients may have >1 diagnoses so total percentiles will be >100%.

p-value = 0.0007), non-English speaking (compared to English speaking: OR, 1.8; 95% CI, 1.1–3.1; p-value = 0.03), and non-White (compared to white: OR 6.6; 95% CI 1.3–32; p-value = 0.02). Of note, there was a high degree of overlap between these groups; of the 109 uninsured patients, 79 identified a language other than English as their primary language.

During the study period, 58 patients (25%) underwent primary repair, 48 were surgical, and 10 were transcatheter. At the end of the study period, 88 patients were left unrepaired; 36 of those patients would be recommended to have their lesions repaired based on American Heart Association/American College of Cardiology guidelines.

In total, 69 patients (30%) had cardiac surgery prior to the study period and 57 (25%) had cardiac surgery during the study period. The most common cardiac operations performed during the study period were atrial septal defect repairs (N = 23), aortic valve operations (N = 13), and tricuspid valve repairs (N = 7).

Table 3. Physiological and anatomical stages of the study population based on anatomic-physiologic (AP) classifications

| Adult CHD AP classification | Number | Percentage |
|-----------------------------|--------|------------|
| Physiologic Stage | | |
| A | 87 | 38% |
| B | 77 | 34% |
| C | 60 | 26% |
| D | 5 | 2% |
| Anatomic complexity | | |
| I (Simple) | 81 | 35% |
| II (Moderate) | 135 | 59% |
| III (Great) | 13 | 6% |

Seventeen (7%) patients underwent an electrophysiology study or ablation and 4 patients (2%) had an implantable cardioverter defibrillator or pacemaker procedure. A total of 84 (37%) patients had catheterizations and a total of 102 catheterization procedures occurred during the study period. Eighty one of the catheterizations were diagnostic and 21 were interventional. The most common interventional catheterization procedures performed were closure of atrial septal defects (N = 6), percutaneous coronary intervention (N = 4), and balloon pulmonary valvuloplasty (N = 3).

Of the cardiac surgeries performed during the study period, six (10%) occurred at the affiliated Adult Congenital Heart Association Comprehensive Care Center. Of the therapeutic transcatheter interventions, five (21%) occurred at the Comprehensive Care Center. In all, 28% of patients received some concurrent care at the affiliated Comprehensive Care Center. Payor mix of the group of patients who received care at the Comprehensive Care Center was similar in makeup to the entire cohort: 4 (6%) were insured with Medicare, 18 (28%) were insured with private insurance, and 17 (26%) were uninsured. Demographics were also similar to the overall cohort: 64 (98%) identified as non-White and 24 (52%) patients identified a language other than English as their primary language. The decision to engage the Comprehensive Care Center was made by the adult CHD physicians, often in collaboration with proceduralists, based on the complexity of each individual case and resources needed.

Overall, 178 (78%) patients had adult CHD clinical visits at the frequency recommended by the guidelines throughout the study period. In total, 151 (66%) patients had echocardiograms and 129 (56%) had electrocardiograms at the guideline-recommended frequency throughout the study period. The proportion of patients who had guideline-recommended adult CHD visits, echocardiograms, and electrocardiograms was significantly lower for those with more advanced physiological stages (Table 4). There was no significant difference in adherence to guideline-recommended adult CHD visits for uninsured patients compared to insured patients (p-value = 0.82), non-White patients compared to White patients (p-value = 0.99), and Non-English-speaking patients compared to English-speaking patients (p-value = 0.93). Similar findings were also observed with regards to guideline-recommended echocardiograms and electrocardiograms; guideline adherence did not correlate with insurance status, White race, or English as a primary language (Table 5). Finally, and of note, adherence to guideline-recommended adult CHD visits,

Table 4. Adherence to guideline-recommended follow-up and testing throughout the study period based on physiological stage

| | Physiological stage | | | P-value |
|---|---------------------|---------------------|-------------------------|----------|
| | Stage A, N = 87 (%) | Stage B, N = 77 (%) | Stage C & D, N = 65 (%) | |
| Adherence to guideline recommended ACHD visits | 82 (94%) | 57 (74%) | 39 (60%) | <0.00001 |
| Adherence to guideline recommended echocardiograms | 70 (80%) | 55 (71%) | 26 (40%) | <0.00001 |
| Adherence to guideline recommended electrocardiograms | 60 (69%) | 42 (55%) | 27 (42%) | 0.003 |

Chi-square tests were performed to compare the distributions of categorical variables.

echocardiograms, and electrocardiograms did not correlate with Comprehensive Care Center utilisation (Appendix 1).

The patients with pulmonary hypertension were analysed as a subgroup to evaluate adherence to medical therapies since pulmonary hypertension has a well-defined medical therapy regimen. Of the 24 patients with pulmonary hypertension, 11 were prescribed medications for treatment: 11 were taking phosphodiesterase type inhibitors (sildenafil or tadalafil), 4 were taking endothelin receptor antagonists (bosentan, ambrisentan, or macitentan), and 1 was taking a prostacyclin receptor agonist (selexipag).

Throughout the study period, there were 0.61 emergency department visits per person-years and 0.49 hospitalisations per person-years. Rates of emergency department visits were similar in patients who were adherent to guideline-recommended adult CHD visits compared to those who were non-adherent (0.62 emergency department visits per person-years versus 0.59 emergency department visits per person-years). Similar findings were also observed with regards to rates of hospitalisations for those who were adherent to guideline-recommended adult CHD visits versus those who were non-adherent (0.47 hospitalisations per person-years versus 0.55 hospitalisations per person-years).

Discussion

To the authors' knowledge, this study is the first to characterize in detail the administration of adult CHD speciality care to an underserved population in a public health system. In this cohort of patients, we found a high proportion of non-White, non-English speaking, and uninsured patients. Additionally, a high proportion presented with unrepaired primary lesions. This latter finding is consistent with previous data showing that patients with lower socio-economic status and public insurance were less likely to have a prenatal diagnosis of a critical CHD.^{3,8}

Overall adherence to guideline-recommended clinical visits, echocardiographic, and electrocardiographic surveillance was high regardless of insurance status, primary language, or White versus non-White race. Over three-fourths of the study population received guideline-recommended adult CHD visits and over half received guideline-recommended echocardiograms and electrocardiograms over the duration of the study period, which included the start of the COVID-19 pandemic. Socio-economic status and financial hardship can be associated with adverse outcomes, financial distress, and delays in care in the adult CHD population.^{3,4,9} Through this lens, these results suggest an effective safety net for a vulnerable population. Indeed, frequency of preventative surveillance was not found to be associated with insurance status or primary language.

It is notable that adherence to guideline-recommended surveillance was negatively associated with more advanced physiological stage. A similar finding was noted in a study

from Oregon that demonstrated low rates of guideline adherence among patients with high anatomic complexity. In that study, 13.4% of patients with Eisenmenger syndrome/cyanosis, single ventricle/Fontan, or transposition of the great arteries seen at a speciality centre were found to have had guideline-indicated echocardiograms.¹⁰

There are a few potential explanations for this. On the one hand, an advanced physiological stage, which is to say worse clinical status, may result from missed preventative care. The no-show rate in the speciality clinic is 33%. On the other hand, the ACC/AHA Guidelines advise more frequent surveillance in those with advanced physiological stages. Adherence to a more rigorous schedule might be more difficult for both patient and provider, as well as the healthcare system itself, which must accommodate more frequent examinations.⁷ The challenges may quickly compound for patients. Adult CHD patients with complex lesions can face particular difficulty with employment and insurability.^{11,12} Our findings suggest that patients with more advanced physiologic stages would benefit from more attention and more dedicated resources to ensure timely and appropriate care.

It is notable also that in 36 of 146 patients with unrepaired defects, a quarter were left unrepaired when a repair was indicated. This may have been due in part to loss of follow-up, but focused efforts are warranted to ensure necessary procedures are completed when indicated.

While collaboration with the affiliated Adult Congenital Heart Association-accredited Comprehensive Care Center was utilised in a minority of cases, this collaboration is considered essential. Beyond transfer of care for complex procedures, numerous non-quantifiable benefits undoubtedly arose from this collaboration. Consultative advice could be sought from specialists at the private academic centre; patients could be presented at multidisciplinary CHD medical-surgical conference; and nurse practitioners employed by the affiliated private hospital could on occasion assist in patient care. These factors all contributed to the success of the safety net clinic. Notably, the accessibility of the Comprehensive Care Center did not correlate with any of the identified socio-economic factors, suggesting the centre served as an unbiased support to the public clinic.

Limitations

There are several important study limitations. As a single-centre study, findings may not be generalisable to other safety net hospital systems. Data on mortality could not be obtained since a high proportion of the patients seen in the NYC Health + Hospitals Corporation clinic were undocumented and there was also a lack of data from outside hospitals and home deaths. One mortality was recorded within the NYC Health + Hospitals Corporation system for an adult CHD clinic patient during the study period. The study

Table 5. Adherence to guideline-recommended follow-up and testing and repair status throughout the study period based on insurance status, race, and primary language. Chi-square tests were performed to compare the distributions of categorical variables

| | Total, N = 229 (%) | Insurance Status | | Primary Language | | Race | | P-value |
|---|-----------------------|-------------------------|---------------------------|-------------------------|-----------------------------|---------------------|---------------------------|---------|
| | | Insured, N = 120 (%) | Uninsured, N = 109 (%) | English, N = 100 (%) | Non-English, N = 129 (%) | White, N = 9 (%) | Non-White, N = 220 (%) | |
| Guideline-recommended ACHD visits | 178 (78%) | 94 (78%) | 84 (77%) | 78 (68%) | 100 (78%) | 7 (78%) | 171 (78%) | 0.99 |
| Guideline-recommended echocardiograms | 151 (66%) | 75 (63%) | 76 (70%) | 63 (63%) | 88 (68%) | 4 (44%) | 147 (67%) | 0.17 |
| Guideline-recommended electrocardiograms | 129 (56%) | 67 (56%) | 62 (57%) | 61 (61%) | 67 (52%) | 5 (56%) | 124 (56%) | 0.96 |
| Unrepaired prior to presentation | 146 (64%) | 64 (53%) | 82 (75%) | 56 (56%) | 90 (70%) | 2 (22%) | 144 (65%) | 0.008 |

was also limited to patients who had at least one visit to the adult CHD speciality clinic; individuals who were not established in the speciality clinic were not included in the data set. Due to the incomplete diagnosis coding in the electronic medical record, a comprehensive list of adults with CHD in the NYC Health + Hospitals Corporation seen outside this speciality clinic was unable to be obtained. Additionally, the referral and enrollment processes were not accounted for and may have biased the population's anatomic complexity or clinical status. Another limitation is that this study was underpowered in regards to demonstrating a difference between adherence and outcomes including rates of hospitalisations and emergency department visits, and future studies should be designed with this population in mind for further investigation. Finally, it should be noted that this study also coincided with the COVID-19 pandemic and patients may have had increased difficulty accessing services during the study period.

Conclusion

In this public hospital adult CHD clinic, a high proportion of patients were uninsured, non-White, non-English speaking, and presenting with unrepaired primary defects. Despite socio-economic barriers and the high resource utilization of the adult CHD population as a whole, guideline-recommended surveillance was administered to the majority of patients. Collaboration with the affiliated Comprehensive Care Center was utilised for 28% of patients and 13% of invasive procedures. Particular attention and resources must be dedicated to patients with advanced physiologic stage to ensure appropriate surveillance. These results can inform the provision of adult CHD care in other public health system settings.

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Competing interests. None.

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