

Brandon Wright, MD  
ECU Pediatrics, PGY-3



# HEALTH SYSTEM ENCOUNTERS AFTER LOSS TO CARDIOLOGY FOLLOW-UP AMONG PATIENTS WITH CONGENITAL HEART DISEASE

Brandon Wright, MD; Carly Fassler, BS; Dmitry Tumin, PhD; Lauren A. Sarno, MD

# BACKGROUND

- Nearly 1% of children in the US are born with a congenital heart defect (CHD)<sup>1</sup>
- Of children with critical CHD (requiring intervention before the age of 1 year), 69% will survive into adulthood, compared to 95% of those with non-critical CHD<sup>2</sup>
- Compliance with pediatric cardiology appointments in this patient population increases survival and health status<sup>3-6</sup>
- Heightened compliance of follow-up has been observed in certain patient populations:
  - Greater severity of CHD, medication prescriptions, completing transition of care from pediatric to adult cardiology, and living closer to their cardiology clinic<sup>7,8</sup>

# BACKGROUND

- Patients with CHD have reported various reasons for not maintaining follow-up:
  - Feeling they were “cured”, moving away, fear of learning their condition has worsened, and not being told they need to follow-up with adult cardiology
- When lost to follow-up, this patient population has a threefold increase in Emergency Department (ED) visits<sup>9</sup>
- Patients living in rural areas such as ours are more likely to cite distance to care and loss of income related to taking time off work as barrier to care<sup>10</sup>

# OBJECTIVES

- Determine how frequently our patients with CHD that were lost to follow-up continued to receive care within our healthcare system at ECU Health
  - Inpatient, outpatient, and ED settings were included
- Describe the most common encounter types and locations
- Discover any clinical or demographical factors associated with patients that continued to receive care in our health system despite no longer attending outpatient cardiology visits

# OBJECTIVES

- We seek to identify factors associated with those patients who have been lost to cardiology follow-up but continue to receive care elsewhere within our health system
- Using this data, we will be better equipped to establish future interventions to improve visit adherence rates within our cardiology clinic

# METHODS

- ECU Pediatric Cardiology clinic provides care to the pediatric population of eastern North Carolina in addition to adults who have transitioned to the Adult Congenital Heart Disease Clinic (ACHD)
- We screened all patients who had at least one visit to ECU Pediatric Cardiology clinic from 1 January 2018 to 31 December 2018
- Data was collected via manual review of the Electronic Health Record

# Study Inclusion Criteria

**451**

Patients with CHD were identified via manual chart review

**27**

Not found to have CHD

**177**

Found not to require further  
cardiology follow-up

**6**

Not yet due for next  
recommended follow-up

**6**

Patients known to have  
transferred care

**235**

Patients included in final analysis

# METHODS

- Demographical data: age, sex, ethnicity
- Clinical characteristics: comorbidities, complexity of CHD, date of surgical intervention
  - Comorbidities characterized as neurological, gastrointestinal, renal, etc
- Socioeconomic characteristics: patient insurance coverage type, median household income (MHI) in the ZIP code of residence, and distance from patient's home to our clinic based on zip code



# METHODS

- Data were summarized as medians with interquartile ranges (IQR) for continuous variables and counts with percentages for categorical variables
- On bivariate analysis, we compared patient characteristics according to whether patients had any subsequent encounters in the ECU Health system
- Continuous data were compared using rank-sum tests and categorical data were compared using Chi-square or Fisher's exact tests
- We then fit a multivariable Cox proportional hazards model to characterize how patient characteristics at the most recent cardiology visit were associated with subsequent hazard of returning to another ECU Health clinical site

Variable	Patients who did not return to visit other clinical sites (N=139)	Patients who returned to visit other clinical sites (N=96)	P
	Median (IQR) or N (%)	Median (IQR) or N (%)	
<b>Age (years)</b>	<b>10 (2, 17)</b>	<b>4 (0, 13)</b>	<b>&lt;0.001</b>
<b>Sex</b>			0.232
Female	76 (55%)	60 (63%)	
Male	63 (45%)	36 (38%)	
<b>Race/ethnicity</b>			0.057
Non-Hispanic White	73 (52%)	40 (42%)	
Non-Hispanic Black	46 (33%)	44 (46%)	
Hispanic	8 (5%)	9 (9%)	
Other	12 (8%)	3 (3%)	

Comorbidities <sup>a</sup>	Patients who did not return to visit other clinical sites	Patients who returned to visit other clinical sites	P
Cardiovascular (other than CHD)	21 (15%)	14 (14%)	0.912
<b>Genetic</b>	<b>12 (8%)</b>	<b>18 (18%)</b>	<b>0.022</b>
<b>Developmental</b>	<b>8 (5%)</b>	<b>14 (14%)</b>	<b>0.038</b>
Pulmonary	10 (7%)	11 (11%)	0.260
GI/hepatic	5 (3%)	9 (9%)	0.091
Behavioral	7 (5%)	6 (6%)	0.775
Renal	8 (5%)	5 (5%)	0.550
Neurologic	4 (2%)	8 (8%)	0.075
<b>HENT</b>	<b>1 (1%)</b>	<b>10 (10%)</b>	<b>&lt;0.001</b>

CHD complexity	Patients who did not return to visit other clinical sites	Patients who returned to visit other clinical sites	P = 0.421
Simple	78 (56%)	61 (64%)	
Moderate	47 (34%)	29 (30%)	
Severe	14 (10%)	6 (6%)	
History of cardiac surgery			0.005
None	92 (66%)	79 (82%)	
>10 years ago	27 (19%)	5 (5%)	
Within last 10 years	20 (14%)	12 (12%)	
Medicaid insurance	66 (47%)	66 (69%)	0.001
Median household income (\$) <sup>b</sup>	45,642	41,466	0.384
Distance to clinic (km) <sup>b</sup>	56 (42, 89)	31 (16, 59)	<0.001
Recontact attempt by cardiology clinic <sup>c</sup>	21 (15%)	13 (13%)	0.737

# RESULTS

- Ninety-six (41%) patients were seen in another clinical setting within our ECU Health system
- Among them, the median number of visits was 3
- Most commonly, patients were seen in subspecialty clinics (n=46), ED (n=44), and primary care clinics (n=40)

# RESULTS

- Patients with history of cardiac surgery  $> 10$  years ago were less likely to receive care elsewhere
- Patients seen at other clinical sites (compared to those who were not), were more likely to be younger, have Medicaid insurance, live closer to our hospital campus, and have more medical comorbidities (specifically HENT, genetic, and developmental)

# DISCUSSION

- Our study sought to determine patterns of care received within the same health system among patients with CHD lost to follow-up at a pediatric cardiology clinic serving a predominantly rural and historically disadvantaged region
- Nearly half of patients in our study were seen elsewhere in the health system after loss to cardiology follow-up
- Considering these patients are frequently seen in other clinical settings, great multidisciplinary collaboration can improve identification of patients lost to cardiology follow-up and help to re-establish care

# LIMITATIONS

- Data is limited to a single hospital system that serves a large, rural catchment area
- Retrospective analysis of data
- Inability to assess whether a patient is following with another hospital system
- Many patients' follow-up dates fell in early-to-mid 2020 during the height of the COVID-19 pandemic
- Some patients likely returned to clinic after the end of the study period



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**QUESTIONS?**