Gaps in Care in Transition Aged and Adult Congenital Patients: Where Do We Start?

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BACKGROUND

- Transition and transfer of care for young adults with congenital heart disease (CHD) is a high-risk period for gaps in clinical care
- Gaps result in long-term morbidity and mortality
- Identifying emerging transition-aged and new adult congenital heart disease (ACHD) patients at risk for gaps is critically important for the CHD population

PURPOSE

- Primary Aim: To identify pre-transition, transition-aged, and young ACHD populations who have experienced gaps in care of at least 1 year
- Secondary Aim: To identify sociodemographic factors associated with having gaps in care in these populations

METHODS

- Retrospective chart review of outpatient electronic medical record (EMR) at Texas Children's Hospital from 2016-2019
- Inclusion Criteria: 10 – 26 years of age at time of cardiology outpatient encounter, CHD (based on ICD 9/10 codes), seen in outpatient cardiology clinic between 2016-2019
- Exclusion Criteria: S/p heart transplant or VAD, non-CHD subspecialty encounter types (electrophysiology, lipids)
- Primary outcome variable: at least one gap in care (≥1 year between requested follow-up and subsequent outpatient cardiology encounter)
- Primary predictor variables: age, gender, race/ethnicity, insurance, CHD complexity, and CHD provider (e.g. ACHD)
- Patients were stratified into age groups: pre-transition (10-12 yrs), early transition (13-15), mid-transition (16-18), late transition (19-20), and early adults (21-26)
- Univariable and multivariable logistic regression models used to determine significant associations between predictor and outcome variables

	n	Gap in Care	Univariate		Multivariate	
			OR (CI)	p value	OR (CI)	p value
Gender:						
Male	1059	501 (47%)	ref	-	ref	-
Female	851	353 (41%)	**1.27 (1.06 – 1.52)**	**0.01***	1.20 (1.00 – 1.44)	0.056
Race:						
White	1536	690 (45%)	ref	-	-	-
Black or African American	230	107 (47%)	1.07 (0.81 – 1.41)	0.649	-	-
Asian	79	32 (41%)	0.83 (0.53 – 1.32)	0.442	-	-
Other	7	3 (43%)	-	-	-	-
Unable to Obtain	56	21 (38%)	0.74 (0.42 – 1.28)	0.274	-	-
Ethnicity:						
Non- Hispanic	725	314 (43%)	ref	-	-	-
Hispanic	1142	526 (46%)	0.89 (0.74 – 1.08)	0.245	-	-
Unable to Obtain	43	14 (33%)	0.57 (0.3 – 1.08)	0.085	-	-
C HD Complexity:						
Simple	158	53 (34%)	ref	-	ref	-
Moderate	1280	551 (43%)	**1.50 (1.06 – 2.12)**	**0.023***	1.42 (1.00 – 2.02)	0.052
Great	472	250 (53%)	**2.23 (1.53 – 3.25)**	**<0.001***	**2.04 (1.39 – 3.00)**	**<0.001***
Age Groups:						
Pre-Transition (10-12 yrs)	609	245 (40%)	ref	-	ref	
Early Transition (13-15 yrs)	510	241 (47%)	**1.33 (1.05 – 1.69)**	**0.018***	**1.30 (1.02 – 1.65)**	**0.035***
Mid-Transition (16-18 yrs)	380	185 (49%)	**1.41 (1.09 – 1.82)**	**0.009***	**1.37 (1.05 – 1.77)**	**0.019***
Late Transition (19-20 yrs)	143	66 (46%)	1.27 (0.88 – 1.84)	0.196	1.20 (0.83 – 1.74)	0.337
Early ACHD (21-26 yrs)	268	117 (44%)	1.15 (0.86 – 1.54)	0.343	1.05 (0.78 – 1.41)	0.765
Preceding Provider:						
ACHD	331	144 (44%)	ref	-	-	-
Pediatric	1579	710 (45%)	1.06 (0.84 – 1.35)	0.628	-	-
Insurance Status:						
Public	736	327 (44%)	ref	-	-	-
Private	1117	502 (45%)	1.02 (0.85 – 1.23)	0.828	-	-
Other	57	25 (44%)	0.98 (0.57 – 1.68)	0.934	-	-

Fig 1: Gaps in care between genders seen in outpatient cardiology clinic between 2016-2019

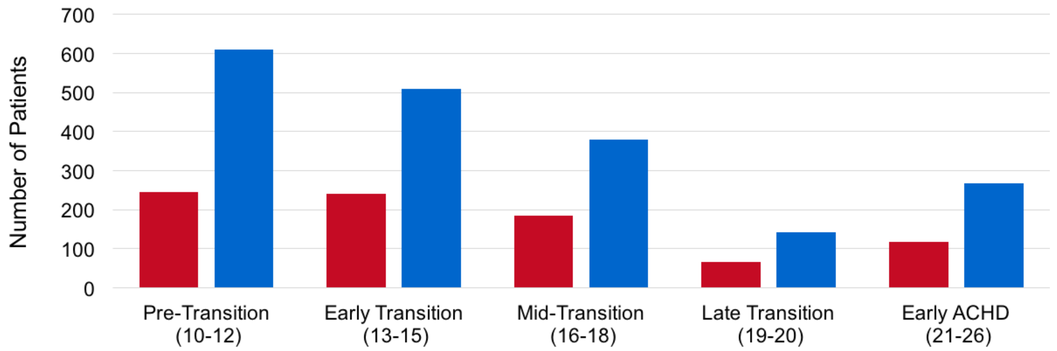

Fig 2: Gaps in care between age groups seen in outpatient cardiology clinic between 2016-2019

RESULTS

- 1910 patients with CHD identified. ~47% were male and the median age of the patients was 15 years
- Approximately 45% of all patients had at least one gap in care with 57% of those experiencing their first gap in pre-transition or early transition periods
- When compared to the pre-transition group, those in early and mid-transition were 30% and 37% more likely to have gaps, respectively
- Patients with complex CHD were twice as likely (OR: 2.04) to have a gap when compared to those with simple CHD (p<0.001)
- There was no significant difference in frequency of gaps in care based on race/ethnicity, insurance status, or care from a pediatric versus ACHD provider

LIMITATIONS

- Retrospective data collection reliant on accurate ICD coding
- Unanticipated hospitalizations between outpatient visits may result in false appearance of a gap in care
- Unable to know reasons for a gap in care in EMR (e.g. death, transition to provider outside TCH, etc)

CONCLUSION

- Transition-aged and early ACHD patients undergo gaps in care earlier than expected, especially with complex disease
- Targeting older teenagers for transition may fail to reduce gaps in care
- This data will be used to identify key drivers and design quality initiatives to reduce care gaps

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