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) encompasses a high-risk period for having gaps in care. Identifying CHD and emerging adult congenital heart disease (ACHD) patients at risk for gaps is critically important for this growing population. The goal of our study was to identify pre-transition, transition-aged, and young ACHD populations at risk for experiencing cardiac care gaps to target a quality improvement (QI) initiative for maintaining appropriate care.

Materials/Methods: We performed a retrospective outpatient electronic medical record (EMR) review at Texas Children's from 2016-2019. CHD diagnoses were identified by ICD codes and categorized into simple, moderate, and great complexity. Age groups stratified into: pre-transition (10-12 yrs), early transition (13-15), mid-transition (16-18), late transition (19-20), and early adulthood (21-26). Primary outcome variable was a gap in care (≥1 yr between requested follow-up and subsequent encounter). Univariable and multivariable logistic regressions were used to determine associations between outcome and predictors: age, gender, race/ethnicity, insurance, CHD complexity, and ACHD care.

Results: 1910 CHD patients identified. Median age was 15 yrs and 55% were male (n=1059). Pre-transition patients were 32% (n=609) with remaining groups: 27% early transition, 20% mid-transition, 8% late transition, 14% early adulthood. Non-Hispanic whites were 43% (n=817). CHD groups were: 8% simple, 67% moderate, and 25% great complexity. About 45% (n=854) had at least one gap with 57% (n=486) of those experiencing their first gap in pre-transition or early transition. On univariable analysis, male gender, older age, and higher disease complexity predicted gaps. On multivariable analysis, when compared to pre-transition, 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 simple (p<0.001). There was no significant differences in gaps based on gender, race/ethnicity, insurance, or ACHD provider care.

Conclusions: This data suggests the EMR can identify patients at risk for gaps in care, and transition-aged and early ACHD patients undergo gaps earlier than previously expected, especially with complex disease. We plan to use this knowledge to identify key drivers, and design QI initiatives focused on a younger cohort than traditionally deemed transition-aged, with the aim of reducing care gaps.