

Prevalence and predictors of lapses in care in adults with congenital heart disease (The Health, Education and Access Research Trial: HEART-ACHD)

Background: Adults with congenital heart disease (ACHD) are at risk for interruptions in care. We undertook a prospective multi-center study, a main objective of which was to quantify the prevalence of lapses in any cardiology care, identify predictors of lapse, and assess barriers to care.

Methods: A study cohort was created by recruiting adults (≥ 18 y) upon their first presentation to a participating ACHD clinic from 1/2009 – 12/2010. Subjects completed a survey regarding lapses in care and barriers to care. Variables collected included sex, race, ethnicity, education level, referral source, up to 5 congenital heart diagnoses (categorized in 3 levels of complexity), and reasons for leaving and returning to cardiology care.

Results: A total of 922 subjects (54% female, 83% white/non-Hispanic) were recruited from 12 ACHD centers. A >3 year lapse in care was identified in 42%, with 8% having lapses >10 years. Mean age at first lapse was 19.9 years (median 19Y). Subjects were highly educated with 73% having more than high school education. Almost 75% were referred by a healthcare provider with 31% from general adult cardiology, 30% from pediatric cardiology, and 13% from primary care. Most subjects (75%) knew the name of their heart condition. The most influential reasons for lapse were (1) felt well, (2) did not think follow-up was required, (3) not having any medical care during lapse. On univariate analysis, disease complexity was predictive of lapse in care with 59% of mild, 42% of moderate and 26% of severe disease subjects reporting lapses in care ($p < .0001$). Clinic location was also a significant predictor ($p < .0001$). Gender, race, education level, and knowledge of disease name were not predictive. Most common reasons for returning to care were (1) new symptoms, (2) referral from provider, (3) hope to prevent future problems.

Conclusions: ACHD patients often have lapses in cardiology care. A first lapse most commonly occurs around age 19 years, concurrent with the time of transition from pediatric to adult providers. Lapses were more common among those with moderate and mild complexity diagnoses and at certain clinic locations. These results provide a framework for developing strategies to decrease lapses and barriers in care in the adult congenital population.