Increased Transition to Adult Care After Interrupted Aortic Arch Repair in a Multi-institutional Cohort


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Objectives: Improved survival after congenital heart disease (CHD) surgery has led to the need for deliberate transition to adult congenital heart disease (ACHD) care. We examined this transition in young adults after repair of interrupted aortic arch (IAA), focusing on the differences between Canadian and other American residents.

Methods: Survivors followed into adulthood from a Congenital Heart Surgeons Society (CHSS) inception cohort of neonates (1987-1997) with IAA completed a CHSS developed questionnaire on transition to ACHD care (n=75, age 18-24 years; 12% (9/75) Canadian, no difference in age by Canadian vs. U.S., p=0.1). Details regarding current care, first ACHD care experience, psychosocial factors, and parental involvement were collected. Features related to demographics, cardiac morphology, index IAA repair, subsequent procedures (interventional and surgical), country of residence and institution were explored for association with time related transition to ACHD care (TRTTAC).

Results: The study population included 65 U.S., 1 Brazilian, and 9 Canadian (8/9 from a single institution) patients. Of the patients who responded, 53/73 (73%, question not answered (QNA)=2) still received their primary cardiac care from a pediatric cardiologist, and 43/66 (65%, QNA=9) have never had any form of adult cardiac care. Of the 21/75 (28%) patients who transitioned to adult care, 12 (57%) reported referral from a pediatric hospital. Of these 12, 5 (42%) were from Canada. Of the same 21 patients, 18 (86%) were referred on a non-emergent basis. Of these 18, 8 (44%) were from Canada. TRTTAC was completed in 10% of the total cohort of patients by age 18, 23% by age 20, and 32% by 21. The only factor associated with TRTTAC was living in Canada (p=0.003) (Figure), with 84% of Canadian patients and 23% of U.S. patients transitioning by age 21.

Conclusions: The system of care at a particular institution may account for the differences seen between countries given the preponderance of Canadian patients from a single institution. While transition to ACHD care is evolving and can be accomplished effectively within many clinical models, the high proportion of TRTTAC in Canada highlights a model warranting further investigation.