Proposed Analysis of the Transition Process from Pediatric to Adult Care for Patients with Congenital Heart Disease in Israel

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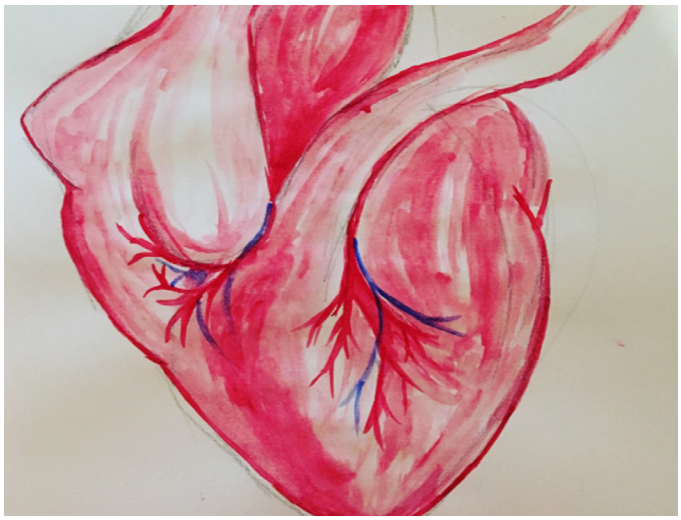
The global prevalence for congenital heart disease is 9 per 1000 live births, making it the most common congenital anomaly in the world (1). Due to medical advances, individuals with CHD are living longer than ever, with over 90% reaching adulthood. It is estimated that within the next decade, nearly 1 in 150 young adults will have some form of CHD. More than 50% of these individuals will be vulnerable to complicated co-morbidities later in life stemming from their CHD, such as hypertension, pulmonary, renal, and myocardial disease, and coronary artery disease, and therefore need to be seen regularly and followed for life by cardiologists (2).

However, despite a clear need for follow-up among a large portion of the population, patients suffering from CHD often go without it, having been lost during the transition from pediatric to adult care. This phenomenon of loss to follow-up during transition has been noted in several countries, though the results differ. In Belgium, one study found the percentage of patients with CHD lost to follow-up to be 7.3% (3), while a study concerning American patients with CHD found that 18% had no cardiology visit within 2 years (3-4). The percentage of patients lost to follow-up in Canada was explored in two studies, which recorded that 27% and 61% of patients over the age of 18 had no cardiac follow-up (5-6). Even when the transition occurs within a single institution, nearly half of these patients will be lost to follow-up (7).

This issue has been difficult to address, in part, because of the non-standardized definition of "loss to follow-up" among different studies. Heery, et al., makes note of some these definitions, including no cardiac consultation after leaving pediatric care, no cardiac consultation since 18th birthday, and



Karen Arane: *He***art**

no cardiac follow-up within two years of interview (1). That paper concludes that this area of research requires for a large, multicenter, international study with standardized definitions in order to be properly researched.

The topic of the 32nd annual meeting of the American College of Cardiology in 2000 was the needs of adults with congenital heart disease. Task Force 2, a steering committee of pediatric cardiologists, concluded that "managing the transition to adulthood begins in childhood" and that an effective transition program would include the following six elements: a set time for transition to adult care, a preparation period and education program for patient and family, a coordinated transfer process (including a written plan, pre-transfer visits, introduction to the adult provider, and a designated coordinator), an adult center of equal quality to the one the patient is leaving, administrative support, and primary care

involvement (8). However, a study conducted in 2008 examining pediatric cardiology programs in the United States and Europe found that among centers that reported transferring patients into adult care, of which three-quarters of the centers in the study claimed to do, only one-third provided structured preparation for patients and family (9). While more than half of the centers had plans to develop formal transition programs, there is still a concerning lack of programs in place and a lack of data concerning which programs are the most effective.

Further complicating the issue is the fact that young patients with stable CHD rarely seek medical follow-up because they tend not to experience symptoms (10). Yet it has been shown that a lapse in care among patients with CHD was associated with a 3.1-fold increase in urgent cardiac intervention (11). One can argue the importance of successful transfer and follow-up among this population is not only crucial to the patient, but to the economics of the health care system as well, because the cost of these urgent interventions may exceed the cost of secondary prevention (12).

Currently, there is no published data concerning the rates of successful transitioning from pediatric to adult cardiology among patients with CHD in Israel. In 2012, the prevalence of CHD in Israel was 5.6 per 1,000 live births, making it by far the most common malformation present among live births (13). Given that there were 170,940 live births in Israel in 2012, there would be nearly 1,000 children born with CHD that year alone. According to Schneider Children's Medical Center, about 70% of Israeli children with CHD are treated in their cardiac intensive care unit, the largest of its kind in Israel (14). The unit performs more than 500 cardiothoracic surgeries annually on patients until age 18. While half of the patients in the unit are under one year of age, 8% of the patient population consists of adults with CHD. Because of the volume of CHD patients treated at Schneider, it seemed logical to explore the phenomenon of transition from pediatric to adult care by examining a cohort from this hospital.

A study should be done to deduce whether or not there is a problem with transition from pediatrics to adult cardiology among patients with CHD in Israel.

Key Point: Types of Congenital Heart Defects

Congenital Heart Defects: Most Common Congenital Disorder in Newborns

Septal Defects (or "Holes in the Heart"): defect allows blood to mix between the two sides of the heart through either atrial or ventricular septal defects, ASD and VSD, respectively

Patent Ductus Arteriosus: abnormal blood flow occurs between the aorta and the pulmonary artery

- Heart murmur may be the only sign of a PDA

Narrowed Valves (control flow of blood between atria & ventricles and ventricles & pulmonary artery/aorta)

- Stenosis: occurs when the flaps of a valve thicken, stiffen, or fuse together -> valve cannot fully open
- Atresia: valve doesn't form correctly -> lacks hole for blood to pass
- Regurgitation: valve doesn't close tightly -> blood leaks back through valve

Tetralogy of Fallot (A Complex Congenital Heart Defect)

- Combination of
(1) pulmonary valve stenosis
(2) large VSD
(3) overriding aorta
(4) right ventricular hypertrophy

U.S. Department of Health and Human Services, National Institutes of Health, National Heart, Lung, and Blood Institute. (2011). Congenital Heart Diseases. Available from http://www.nhlbi.nih.gov/health/health-topics/topics/chd

The cohort should be stratified based on severity of defect, according to the ACC Task Force 1 report, to keep the data standardized with current practices. Examining variables such as socioeconomic status, geographic distance from institution, and living arrangements upon leaving home, would allow for the identification of associations that could predict patients who are high risk for failure to follow-up. This will help to demonstrate the need for follow-up and provide quantitative evidence of the consequences when the process fails.

This research would be the beginning of Israel's contribution to the ongoing research concerning the transition to adult care among the CHD population. Immediately, the conclusions of this research would allow reasons for transition failure to be addressed, potentially helping thousands of children and adults. There is the hope that because Israel is a small nation, it can establish a formal transition program quickly. Once in place, we can gain more understanding of what aspects make a program most effective, and whether these structured transitions have true benefit. On an international scale, once the data collected in our study becomes available, Israel will be able to participate in future large, multinational studies that are needed in the field, further diversifying the cohort and allowing for more generalized conclusions.

Key Point: Pulse Oximetry for CHD Detection

Pulse oximetry screening (in all newborns after 24 hours of life or as late as possible if early discharge is planned) targets defects that require intervention in the first year of life and may present with hypoxemia, or low level of oxygen in blood.

Screening with pulse oximetry was better at identifying infants with critical CHD than with just physical examinations.

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