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Project Title: "Pediatric Heart Transplant Recipients Transitioning to Adult Care"

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Research Question: Does quality of life suffer in pediatric heart transplant patients transitioning to adult care and how can we make improvements?

Background: The transition from adolescence to adulthood in general can be characterized by the terms "risk and vulnerability", and the transition from more protected pediatric health care to more independent, adult health care is an added challenge. This time period poses risk for poor judgement, risk taking behaviors, and emotional reactivity, all of which can make it difficult to partake in and understand one's own complex care. Twenty years of national child health surveys and state and community studies continue to demonstrate that most youth and young adults with special health care needs (SHCN) and families do not receive the support they need in the transition from pediatric to adult health care^{3,5}. While there is plenty of existing data on the transition of adolescents with other chronic diseases, even Congenital Heart Disease⁴, there is limited data on the heart transplant recipient population. With advances in science, technology and optimization of medical and surgical care, early post-transplant mortality has improved, resulting in a larger population of pediatric patients moving into adulthood necessitating adult care¹. A retrospective review of heart transplant recipients less than 40 years of age demonstrated graft failure rates that were highest among 17- to 29-year-old patients making this time especially high risk for post-OHT recipients². Columbia University Medical Center has performed hundreds of pediatric heart transplants and therefore has a significant population of patients who have made this transition without a formalized transition process. This study aims to evaluate this vulnerable population to determine quality of life after this transition is made and understand important factors in developing a transition program in this specific institution.

Aims: (1) evaluate quality of life of adolescents preparing to transition and young adult heart transplant recipients who transitioned from pediatric to adult cardiology care within a single institution that provides both practices, prior to a formalized transition process (2) examine patient readiness for transfer of care to adult providers, potential barriers to readiness, and most important factors for a formalized transfer of care process.

Hypothesis: It is expected that there will be a difference in quality of life between pretransition and post transition patients with post transition patients scoring higher on the PedsQL survey indicating worse quality of life.

Methods:

Study Design: Cross sectional descriptive survey. Heart transplant patients who are preparing to transition to adult care at this time and patients that have transitioned from pediatric to adult care between the years of 2011 and 2021 will be asked to fill out surveys related to quality of life and readiness for transfer of care.

Setting: Single academic medical institution, Columbia University Medical Center, that provides both pediatric and adult cardiac care (i.e. Morgan Stanley Children's Hospital and Columbia University Irving medical center).

Study Population: Study subjects are patients who received heart transplants in childhood (prior to 18 years of age) and are now adolescents preparing for transition (Group 1) or are adults (18 years and older) at present date (Group 2) (born on/before January 1, 2003). Group 2 study subjects have received a heart transplant as a pediatric patient and have transferred their

cardiology care from a pediatric to an adult heart transplant/heart failure provider within the last 10 years (from January 1, 2011 to January 1, 2021). All patients will have received their heart transplant at Columbia University Irving medical center (CUIMC) while under the care of a pediatric cardiologist. Eligible subjects in Group 1 will be currently following with a pediatric cardiologist and Group 2 will have had at least one visit with a member of the Columbia University Irving Medical Center adult heart failure and transplantation cardiology team (ex: clinic, echocardiogram, cardiac catheterization, or surgical consultation).

Study Procedures:

Recruitment: Eligible patients will be recruited via mailing of the recruitment letter to the current address on file in the patient's electronic medical record. The recruitment letter will be in "opt out" format, where the patient is given the contact information for the study team, and must take action within the specified 2 week interval if they do not wish to be contacted by the study team about the research study. In accordance with the Institutional Review Board Standard Operating Procedures, if the patient does not opt out of being contacted by the research team, then patients will be contacted by a member of the research team by phone, to describe the research study and ask if they are willing to participate. If the patient is interested in participating in the study, informed consent will be obtained either in person (written), by phone (verbally), or the consent to participate in the study will be implied by the return of completed written surveys or online via Qualtrics.

Surveys: (1) Pediatric Quality of Life Inventory PedsQLTM 3.0 Cardiac Module for either teens (ages 13-18), young adults (ages 18 to 25), adults (ages 26 and older) (2) UNC STARx Questionnaire for Patients in Adult-focused settings OR survey of our own.

Statistical Analysis: The Pediatric Quality of Life Inventory PedsQLTM 3.0 Cardiac Module responses are evaluated using a Likert scale providing quantitative data, we will use mean, standard deviation and independent samples t test. For transition readiness survey, if using the UNC STARx Questionnaire for Patients in Adult-focused settings, we will proceed with similar calculations as above, however, if using our own survey it will more likely be qualitative/descriptive data.

Project Goals:

1. To determine how quality of life is affected by transitioning from a pediatric to adult medical practice.
2. To identify what the most important factors are during this transition that impact patient experience and outcomes.
3. Begin process of developing formal heart transplant transition program at Columbia University Medical Center.

Resources:

1. Dipchand AI, Laks JA. Pediatric heart transplantation: long-term outcomes. *Indian J Thorac Cardiovasc Surg.* 2020;36(Suppl 2):175-189. doi:10.1007/s12055-019-00820-3
2. Foster B.J. et al High risk of graft failure in emerging adult heart transplant recipients. *Am J Transplant.* 2015; 15: 3185-3193
3. Grady KL, Hof KV, Andrei AC, et al. Pediatric Heart Transplantation: Transitioning to Adult Care (TRANSIT): Baseline Findings. *Pediatr Cardiol.* 2018;39(2):354-364. doi:10.1007/s00246-017-1763-x
4. John AS, Jackson JL, Moons P, et al. Advances in Managing Transition to Adulthood for Adolescents With Congenital Heart Disease: A Practical Approach to Transition Program

Design: A Scientific Statement From the American Heart Association. *J Am Heart Assoc.* 2022;11(7):e025278. doi:10.1161/JAHA.122.025278

5. White PH, Cooley WC; Transitions Clinical Report Authoring Group; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics.* 2018;142(5):e20182587. *Pediatrics.* 2019 Feb;143(2):e20183610. doi: 10.1542/peds.2018-3610. Erratum for: *Pediatrics.* 2018 Nov;142(5): PMID: 30705144.