

ACHA 2022 Research Grant Award

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Project Title: *Validating a Patient-Reported Outcomes Tool in Adults with Congenital Heart Disease*

As adults with congenital heart disease (CHD) survive into adulthood, heart failure has become a growing reason for hospitalization and the leading cause of death. The growth of this unique population creates a need for new research strategies to optimize care and improve outcomes. Data are limited on health outcomes and therapeutic options for adults with CHD with heart failure. The lack of validated and sensitive measurements of patient-reported outcomes and health status (e.g., patient symptoms, physical capacity and function, and quality of life) are major barriers to studying health outcomes in adults with CHD. A tool to measure heart-failure specific patient-reported health status is imperative and necessary for monitoring patients' clinical status and symptom burden over time. We hypothesize that a patient reported outcomes tool used in acquired heart failure, the Kansas City Cardiomyopathy Questionnaire (KCCQ), can accurately characterize and quantify symptoms, functional capacity, and quality of life metrics in adults with CHD with heart failure. The goal of this study is to validate a patient-reported outcomes tool in the adult congenital heart disease population with heart failure by comparing KCCQ scores with measurements of ventricular function and functional capacity. By completing this project, we will uncover key insights in being able to quantify CHD patients' perceptions of how heart failure affects their health, functional status, and quality of life. Our results will help clinicians monitor a patient's clinical status and symptom burden over time and identify at risk patients for more intensive heart failure therapies and interventions.