

Provider Research Grant - Matthew Lewis, MD, MPH
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Patient Centered Research Models to Diagnose and Treat Anxiety Disorders in Adult Congenital Heart Disease: A Pilot Pragmatic Clinical Trial

The number of patients with congenital heart disease has increased exponentially over the course of the last 3-4 decades, and there are now more adults with congenital heart disease than children. Because of prior interactions with the medical system and the trauma associated with the need for multiple interventions, untreated anxiety disorders are more common in adult congenital heart disease (ACHD) patients. Anxiety disorders negatively affect both follow-up and quality of life, severely impacting the health of this population. Unfortunately, because of lack of recognition and limited access to mental health providers, the vast majority of ACHD patients with anxiety disorders remain untreated. Internet based cognitive behavioral therapy has been shown to have a meaningful impact on individuals with anxiety but has never been trialed in ACHD patients. The goal of this proposal is to leverage peer to peer engagement and patient organizations to a) evaluate how common anxiety disorders are in ACHD patients, b) determine if we can better predict which individuals are at highest risk for anxiety and b) to perform a pilot study assessing the efficacy of internet-based cognitive behavioral therapy treatments for anxiety in the ACHD population.

We will work with patients and patient organizations directly to promote patient participation and will use a HIPPA-compliant, encrypted database to ensure privacy. All patient participants will fill out information in validated assessment tools to provide an accurate assessment of levels of anxiety. Patients who are interested will be eligible to undergo a ten-week internet based cognitive behavioral therapy tool over the internet, with remote therapist back-up. Following, anxiety levels will be reassessed. All patient participants will be reimbursed and will be provided with data derived from the study.

Utilization of internet-based treatment protocols may offer patients a low cost-low barrier option for treatment of a frequently incapacitating health issue. Ultimately, completion of this protocol will significantly improve our understanding of the prevalence and associated co-morbidities of anxiety in the ACHD population, demonstrate the efficacy of collaborative patient-provider research methodology in congenital heart disease, and lay the foundation for a larger grant-funded study to fully test and implement internet-based treatment protocols for mood disorders in ACHD patients.