UCDAVIS HEALTH

CHILDREN'S HOSPITAL

Background

Adults with congenital heart disease (ACHD) often experience interruptions in cardiovascular care. The first gap is commonly recognized during the late teen years, concurrent with the age of transition from pediatric to adult medical care. Patients with complex congenital heart disease (CHD) can become lost to care due to numerous issues including relocating for college/work, inability to work, loss of insurance and inability to get to an ACHD center due to travel limitations when living in remote areas. This leads to increased emergency room visits, increased complications, and overall progression of disease. The goal of this program is to provide a "Medical Home" for ACHD patients in inland Northern California, and to re-engage patients who have been lost in transition



Purpose

As a result of improved interventional and surgical options, there are now more adults living with CHD than children. This has created a question: What specialty is best equipped to care for this complex group of patients as they age out of the pediatric setting? We proposed that the most appropriate medical home for these patients is a comprehensive ACHD program utilizing expertise from both adult and pediatric cardiologists. The UC Davis Pediatric Heart Center, part of the UC Davis Children's Hospital exists within an adult hospital. This designation allows us to capitalize on both pediatric and adult resources available within the institution. Our program is unique as it integrates adult cardiologists with experience in ACHD and pediatric cardiology to bring comprehensive resources to the ACHD population. The goal is to provide the best care possible to this complex population while aiming to reduce healthcare cost.

Designing a Medical Home for Adults with Congenital Heart Disease UC Davis Pediatric Heart Center

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Implementation

Grant funding from the American College of Cardiology Foundation was used to start this quality initiative. Our multidisciplinary group includes board certified specialists in ACHD, adult cardiology, experts in adult congenital heart surgery, interventional cardiology, electrophysiology, onsite echocardiography, nurse practitioner, dietician, pharmacist, and a social worker. The ACHD clinic is strategically located to help ease the transition for young adults with CHD from the pediatric to the adult platform. Patients undergo onsite noninvasive testing and complete medical evaluation. During the visit, the patient and family are provided counselling, resources and leave with a personalized "Patient Passport". At the conclusion of each clinic day, a multidisciplinary conference is held to evaluate and discuss each patient, with interventional and testing referrals made.



Results

Eighty-nine patients with ACHD were identified by searching the Adult and Pediatric Cardiology electronic database at UC Davis. Thirty-five patients who were "lost to follow up" were contacted and are now connected to a medical home. Multiple patients were self-referred or referred by outside providers. The first ACHD clinic was on January 14th, 2022, and the program is now fully booked into 2023. This clinic has resulted in eleven cardiac procedures (one surgical procedure, two cardiac catheterizations, three electrophysiology studies, three pacemaker implants, and two pacemaker generator changes).



DISTRIBUTION OF CHD DIAGNOSIS

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Innovation

"Patient Passport"



Next Steps

- 1) Formalize the inpatient flow design for patients with ACHD during admissions
- 2) Create a tool to aid in communication with referral centers
- 3) Apply for ACHD certification
- 4) Standardize transition process to begin at age 13
- 5) Collect patient satisfaction questionnaires
- 6) Participate in the Fontan Outcomes Network
- 7) CME for adult and pediatric providers regarding ACHD
- 8) Explore outreach services to improve care in rural areas

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