

**Canadian Cardiovascular Society (CCS)
Abstracts — Congenital**

P043

ADULT CONGENITAL HEART DISEASE HEALTH SERVICES IN CANADA-WHERE HAVE WE COME IN THE PAST 15 YEARS

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BACKGROUND: There are more adults than children with congenital heart disease in Canada. Adult Congenital Heart Disease (ACHD) patients are at increased risk of poor outcomes compared to the age matched population and require ongoing specialized care to optimize well-being and survival. Data regarding ACHD clinic evaluation, diagnostic and procedures in Canada has not been well characterized. The purpose of this study is to characterize the current quality of care for ACHD patients.

METHODS AND RESULTS: A survey detailing infrastructure and human resources was sent to all CACH ACHD centers across Canada. The data responses were compared to the previously published data from 2007 to evaluate the evolution in provision of care over the past 15 years. All centers responded (n=16). The total number of active (defined as booked for follow-up) ACHD patients followed in ACHD clinics in Canada is 34 208 (previously 21 897). Median number of patients per clinic = 2400 (IQR: 1050, 2875) (previously 1650; IQR 600,2246). A mean of 6.3 ± 2.4 (adult trained and pediatric trained) MDs are affiliated with each center (previously 7 ± 3). Of the 95 affiliated MDs 46% (n=44) received formal ACHD training (previously 27% (n=22) with ACHD training). For the 2020 calendar year, median number of patients visits per site was 977 (IQR:498,1642), (previously 581, (IQR: 241,1333)). Mean ACHD specific procedural volumes, per site, for 2020 compared previous: diagnostic catheterization = 108 ± 250 (previously 21 ± 33), percutaneous interventions = 31 ± 39 (previously 27 ± 28), surgery = 28 ± 36 , (previously 26 ± 30).

CONCLUSION: Over the past 15 years the number of ACHD patients in Canada receiving specialized care has increased by over 56%. Compared to a decade prior the number of physicians with formal CHD training has increased and there are now more physicians with dedicated training providing care to ACHD. More patients are being evaluated in clinic and undergoing diagnostic and therapeutic procedures.

P044

DETERMINING RESEARCH PRIORITIES WITH TEEN AND ADULT CONGENITAL HEART DISEASE PATIENTS: A MIXED METHODS STUDY

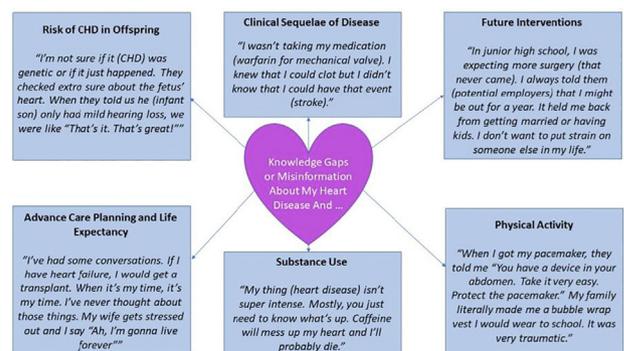
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BACKGROUND: Children with congenital heart disease are living longer than ever before. This growing cohort of adults with CHD has high medical and psychosocial needs. Also, patients and advocacy groups are justifiably demanding their voices be heard in all phases of clinical and health services research. Objectives: 1. To include the patient voice in all phases of the research process. 2. To determine the key needs of patients living with CHD to guide health services research. 3. To identify the “top-ten” research priorities of teens and adults living with CHD.

METHODS AND RESULTS: We conducted a first of its kind research-priority setting exercise with teens and adults with moderate to complex CHD. Focus groups were held using a fixed, mixed methods, exploratory sequential design. Thirty-five patients participated in one of nine 3-hour focus groups where they shared their experiences living with CHD. They expressed a desire for connection with others living with CHD and altruistic motives for participating. CHD patients identified a need for information about their disease and prognosis, a need for connection through physical activity and mentorship programs, and a need for advanced communication with health care teams. Qualitative results correlated well with quantitative ratings to create a patient-derived “Top 10” research priorities list.

CONCLUSION: Conclusions: Patients affected by a chronic disease like CHD want to be included in all phases of research. Our research-priority setting exercise in teens and adults with CHD has created a roadmap for clinicians and researchers to investigate issues of most import to those living with CHD.





Top Priorities for
Teens and Adults
with CHD

Richard Rowe Award Finalist

P045

DOES A SMARTPHONE-BASED ECG RECORDING SYSTEM IN PEDIATRIC PATIENTS WITH PALPITATIONS IMPROVE DIAGNOSTIC YIELD?

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BACKGROUND: Palpitations in children can be caused by benign or malignant heart rhythms. Documenting the rhythm during symptoms (symptom-rhythm correlation) can be diagnostic but may be challenging to achieve. The AliveCor Kardia monitor is an event recorder developed to detect atrial fibrillation in adults, with its utility in children remaining less rigorously studied. We compared use of the Kardia to the Cardiocall event recorder, our institution's current standard event recorder for children with palpitations, through a prospective, randomized study of children presenting to pediatric cardiology for investigation of palpitations who require an event recorder for symptom-rhythm correlation.

METHODS AND RESULTS: Pediatric patients were randomized to receiving the Kardia or Cardiocall event recorder for rhythm documentation. Diagnostic tracings were defined as recording one pathologic arrhythmia or 3 sinus rhythm tracings. We assessed tracing quality, diagnoses obtained, and time to diagnosis between groups. Patients were provided surveys to assess their perceptions of using the devices. Differences between groups were assessed using chi square, Mann-Whitney U, and Fisher exact analysis. Eighty-four participants were enrolled: 43 (51%) receiving Kardia and 41 (49%) Cardiocall devices. There were 148 tracings recorded (84 from Kardia and 64 from Cardiocall devices). Seventy-three (87%) Kardia tracings were of adequate quality for interpretation compared to 58 (91%, $p=0.48$) from Cardiocall. Diagnostic tracings were achieved in 51% vs 34% ($p=0.11$) in the Kardia vs Cardiocall group at medians of 15 (6-39) and 8 (3-21) days, respectively ($p=0.23$). Diagnoses obtained using Kardia vs Cardiocall tracings were sinus rhythm in 67 (80%) vs 57 (81%)

tracings, AVRT or AVNRT in 5 (7%) vs 3 (4%), atrial tachycardia in 2 (3%) vs 0, atrial fibrillation in 1 (1%) vs 0, and indeterminate in 3 (4%) vs 6 (9%), respectively. Patients who used the Kardia monitor were more often willing to use the device again (90% vs 42%, $p=0.012$), with no differences between groups in finding episodes easy to record (74% vs 100%, $p=0.13$), easy to transmit (79% vs 46%, $p=0.11$), or overall satisfaction (75 vs 58%, $p=0.44$).

CONCLUSION: Our preliminary data suggest the Kardia device provided adequate quality for rhythm strip interpretation with no difference compared to the standard Cardiocall monitor. Families who used the Kardia monitor were more willing to use the device again which should be considered when a symptom-rhythm correlation is needed.

P046

EXCESS TIME TO ADULT CONGENITAL HEART DISEASE CARE

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BACKGROUND: Over 90% of children with congenital heart disease (CHD) reach adulthood. Many of these individuals require lifelong cardiology care. Loss to follow-up predisposes patients to late recognition of cardiac complications. However, whether or not a young adult attends an ACHD clinic is a crude outcome variable. Rather, the time between the final pediatric visit and the first ACHD visit, over and above what was recommended by the referring pediatric cardiologist, is a variable that captures not only whether a patient was seen in an ACHD clinic but also the time delay, if any, in arriving there. Predictors of high excess time are unknown. Therefore, we sought to describe the excess time to ACHD care and determine risk factors for elevated excess time.

METHODS AND RESULTS: We conducted a retrospective cohort study including all patients with moderate or complex CHD who were 16-18 years of age at their last pediatric cardiology visit at the Alberta Children's Hospital or Stollery Children's Hospital. We excluded patients known to have relocated outside the catchment area of a study site, or having had a heart transplant. Medical records of the pediatric site and corresponding ACHD clinic were reviewed to determine appointment dates and clinical factors. Excess time between pediatric and ACHD care was defined as the time interval in months between the final pediatric visit and the first ACHD visit, minus the recommended time interval between these visits. Patients who had their first ACHD appointment earlier than the recommended time were assigned an index time of 0. Two hundred and eight-six patients (66% male, mean age 17.6 years at last pediatric appointment) were included of whom 29 (10%) had an index time >24 months. Mean excess time was 7.9 ± 15.9 months. On logistic regression, having a pacemaker was