

**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.

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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.

