



Original Article

Population and Resource Utilization Among Patients With Adult Congenital Heart Disease: A Snapshot View of a Moderate-Size Canadian Regional Centre

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ABSTRACT

Background: Health care resource utilization for patients with adult congenital heart disease (ACHD) has not been well characterized outside of large Canadian specialized regional centres. We sought to describe the ACHD population and resource utilization patterns seen in a medium regional Canadian centre providing specialized ACHD care.

Methods: A cross-sectional retrospective study was done from a sample of patients seen in 2018 at the ACHD clinic in Manitoba, Canada. Demographic data were collected along with cardiac anatomy and

Care of adults with congenital heart disease is a relatively new and growing field. Many of the palliative and reparative surgeries created to save infants and children with congenital heart defects were pioneered within the past 50 years.¹ Only in the past 10 to 20 years have outcomes among adult patients with congenital heart defects been critically evaluated. Despite advances in surgical and interventional repairs, it has been clearly demonstrated that patients with adult congenital heart disease (ACHD) require lifelong specialized health care and are at increased risk of poor outcomes compared to an age-matched population.² Overall, patients with ACHD have a shorter life expectancy, more medical complications, and higher health care costs than their age-matched peers.³⁻⁵

The population and health care catchment area of Manitoba is approximately 1.3 million.⁶ Based on birth rates and survival to adulthood, it is estimated that there are 6700 people with ACHD in Manitoba and surrounding health care catchment areas.⁷ There are approximately 1800 patients receiving specialized ACHD care at the Manitoba ACHD clinic, with an additional 80-100 patients transitioning from

RÉSUMÉ

Contexte : L'utilisation des ressources de santé à l'extérieur des grands centres spécialisés régionaux au Canada n'a pas été bien caractérisée pour les patients atteints de cardiopathie congénitale de l'adulte (CCA). Nous avons cherché à décrire la population atteinte de CCA et les schémas d'utilisation des ressources observés dans un centre régional canadien de taille moyenne fournissant des soins spécialisés en CCA.

Méthodologie : Une étude transversale rétrospective a été réalisée à partir d'un échantillon de patients rencontrés en 2018 dans une

pediatrics to adult care each year. Population in the catchment area that we serve is similar in size to that in many well established specialized ACHD centres. With the growing prevalence of ACHD patients across Canada, it is of value to characterize the health care resource demand required to provide specialized care for them.

The purpose of this study was to evaluate the ACHD population followed by our moderate-size regional ACHD care centre, in order to characterize its demographics, disease complexity, and health care resource utilization. This information is essential in understanding and planning for resource allocation in similar-sized regional centres to provide patients with the accepted standard of specialized care required by adults with ACHD.⁸

Methods

This is a cross-sectional retrospective chart review done from a sample of patients from the Manitoba ACHD clinic between January 1, 2018 and December 31, 2018. Our catchment area includes the whole of Manitoba, as well as a portion of Nunavut, Eastern Saskatchewan, and Northwestern Ontario. Patients were included if they were over the age of 18 years, with documented congenital heart disease (International Classification of Diseases 9th edition codes 745 to 747, and 10th edition codes Q20.0 to Q26.9). The sample was stratified by complexity into groups of simple, moderate, or complex congenital heart disease, per the American College of

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Ethics Statement: Our institutional research ethics board approved this study.

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See page 1137 for disclosure information.

repair type. Health care resource utilization, clinic visits, hospital admissions, unexpected hospital presentations, and cardiac interventions were measured over a 5-year period.

Results: A random sample of 262 patients was selected from our specialized ACHD clinic. Mean age was 33.5 (± 13.7) years; 48% of the population was female, and >50% resided within the major city limits. A total of 21% of the population had simple anatomy, 44% had moderate anatomy, and 35% had complex anatomy. The most commonly used imaging modality was echocardiography, followed by cardiac magnetic resonance imaging, with more frequent imaging done in patients with complex anatomy. Unexpected hospital encounters occurred at a rate of 16 per 100 person-years. Total inpatient hospital days occurred at a rate of 33 per 100 person-years, and visits to the congenital clinic occurred at a rate of 90 per 100 person-years.

Conclusions: Health care resource utilization appears to be highest in older adults and those with more complex ACHD anatomy. As the overall cohort of adults with ACHD continues to age, resource needs are likely to increase.

Cardiology/American Heart Association (ACC/AHA) standardized classification of ACHD disease complexity.⁸ Supplemental Table S1 elaborates on each classification. Our institutional research ethics board approved this study.

The study sample was obtained from randomly selected daily appointment lists of patients seen at our specialized ACHD clinic, as distributed throughout 2018 (Supplemental Figure S1). Once a list was selected, patients on it were included if they had document congenital heart disease, per ACC/AHA classification criteria. For every patient, all relevant medical encounters within the study period were searched on the provincial electronic patient record system and included for data analysis. Outcomes were determined by thorough review of the patient's electronic file. This process involved searching and recording outcomes from all available documents, including consultations, admissions, clinic visits, emergency department encounters, and discharge notes.

Demographic data included age, gender, and area of residence (urban/rural or out of province). We also collected data on lifetime prevalence of cardiac events, including atrial fibrillation as documented by electrocardiogram or ambulatory monitoring, sustained ventricular tachycardia, clinical diagnosis of cardiac syncope, need for pacemaker or implantable cardiac defibrillator, left- or right-sided congestive heart failure as defined by clinical evidence of congestion requiring hospitalization or medical therapy (diuretic therapy for volume overload/congestion), as well as documented endocarditis (positive blood/tissue cultures and imaging evidence of a vegetation). We defined congestive heart failure as pathologic cardiac function resulting in clinical and physiological signs or symptoms indicative of inadequately low cardiac output and pulmonary or systemic congestion at stress or rest. Other non-cardiac comorbidities were recorded, and these included documented depression/anxiety, diabetes requiring medical therapy, self-reported learning difficulty, documented

clinique spécialisée en CCA du Manitoba, au Canada. Des données démographiques ont été recueillies de même que des données sur l'anatomie cardiaque et le type de réparation. L'utilisation des ressources de soins de santé, les visites à la clinique, les admissions à l'hôpital, les consultations hospitalières imprévues et les interventions cardiaques ont été mesurées sur une période de cinq ans.

Résultats : Un échantillon aléatoire de 262 patients a été sélectionné dans notre clinique spécialisée en CCA. L'âge moyen des patients était de 33,5 ($\pm 13,7$) ans; 48 % de la population était de sexe féminin et plus de 50 % résidait dans les limites d'une grande ville. Au total, 21 % de la population présentait une anatomie cardiaque simple, 44 % une anatomie modérément complexe et 35 % une anatomie complexe. La technique d'imagerie la plus utilisée était l'échocardiographie, suivie de l'imagerie par résonance magnétique cardiaque, l'imagerie étant plus fréquente chez les patients présentant une anatomie cardiaque complexe. Le taux de consultations hospitalières imprévues était de 16 pour 100 années-patient. Le nombre total de jours d'hospitalisation était de 33 pour 100 années-patient, et le nombre de visites à la clinique spécialisée en CCA était de 90 pour 100 années-patient.

Conclusions : L'utilisation des ressources de soins de santé semble être plus élevée chez les adultes plus âgés et chez ceux qui présentent une anatomie plus complexe liée à la CCA. Puisque l'ensemble de la cohorte d'adultes atteints de CCA continue de vieillir, les besoins en ressources sont susceptibles d'augmenter.

hypertension and cerebrovascular accident/transient ischemic attack, as well as pulmonary hypertension (mean pulmonary artery pressure >25 mm Hg)

The main outcome of this study was the rate of health care resource utilization per 100 person-years. Resource utilization was calculated based on findings from the 5-year period preceding patients' most recent 2018 clinic visit. The study tracked specialized clinic visits, cardiorespiratory-related emergency room visits, cardiorespiratory-related hospitalizations, length of inpatient hospital stay due to cardiorespiratory reasons, need for out-of-province specialized cardiac care, cardiac procedures, and cardiac imaging. Unexpected hospital encounters is a category created to summarize health care utilization, which was defined as the total sum of unplanned cardiorespiratory-related hospitalizations and emergency room visits. When there was a patient presenting to the emergency room requiring hospital admission, each encounter was counted separately for the same patient. Out-of-province specialized care included congenital cardiac surgery or interventional procedures not available in our regional centre. Diagnostic testing resources that were evaluated included echocardiograms, cardiac computed tomography, cardiac magnetic resonance imaging, graded exercise tests, cardiopulmonary studies, cardiac catheterizations, Holter monitors, and nuclear medicine scans.

Data were reviewed and summarized using means and standard deviations for continuous variables, and percentages for categorical variables. Values were stratified upon convenience age categories (18-30 years, 31-50 years, >50 years) and compared across ACC/AHA disease complexity using a Kruskal-Wallis test, with $P < 0.05$ being considered statistically significant. In an attempt to quantify the total number of health care resources utilized by the entire Manitoba ACHD clinic study population, the total number of patients seen in the specialized ACHD clinic in 2018 were

Table 1. Characteristics of the ACHD Study cohort (time period: January 1, 2018 to December 31, 2018)

Characteristic	ACHD cohort (N = 262)	Simple anatomy (n = 54)	Moderate anatomy (n = 116)	Complex anatomy (n = 92)
Demographics				
Age, y	33.5 (13.7)	34.4 (15.2)	35.2 (14.0)	30.8 (12.1)
18-30	136 (52)	32 (59)	47 (41)	57 (62)
31-50	92 (35)	12 (22)	52 (45)	28 (30)
≥ 51	33 (13)	10 (10)	16 (14)	7 (8)
Gender, female	124 (48)	26 (48)	59 (51)	39 (43)
Area of residence				
Winnipeg	137 (52)	26 (48)	66 (57)	45 (49)
Rural Manitoba	133 (43)	28 (52)	45 (39)	40 (43)
Out of province	9 (3)	0 (0)	4 (3)	5 (5)
Missing	3 (1)	0 (0)	1 (1)	2 (2)
Lifetime cardiac events				
Atrial fibrillation	33 (13)	5 (9)	15 (13)	13 (14)
Sustained VT	2 (1)	0 (0)	1 (1)	1 (1)
ICD/pacemaker implantation	22 (8)	1 (2)	12 (10)	9 (10)
Syncope	21 (8)	1 (2)	9 (8)	11 (12)
Congestive heart failure	16 (6)	0 (0)	6 (5)	10 (11)
Endocarditis	9 (3)	3 (6)	5 (4)	1 (1)
Noncardiac medical history				
Anxiety/depression	32 (12)	5 (9)	13 (11)	14 (15)
Hypertension	26 (10)	4 (7)	17 (15)	5 (5)
Diabetes	19 (7)	3 (6)	9 (8)	7 (8)
Learning difficulties	17 (6)	3 (6)	7 (6)	7 (8)
CVA/TIA	12 (5)	1 (2)	4 (3)	7 (8)
Pulmonary hypertension	10 (4)	1 (2)	3 (3)	6 (5)

Values are n (%), or mean (standard deviation).

ACHD, adult congenital heart disease; CVA/TIA, cerebrovascular accident/ transient ischemic attack; ICD, implantable cardioverter-defibrillator; VT, ventricular tachycardia.

proportionally allocated to age and complexity groups based on the reviewed cohort's distribution, and multiplied by their respective average per 100 person-years values. All analysis was performed using SAS version 9.3 (SAS, St. Boniface Hospital, Winnipeg, MB).

Results

Demographics

A total of 262 patients were randomly selected from the 537 patients seen in the specialized ACHD clinic in 2018. Of the study population, 48% were female, and 52% resided within Winnipeg, the major city where our ACHD clinic is located. The mean age of patients was 33.5 ± 13.7 years, with the complex-anatomy group being the youngest. [Table 1](#) outlines the patient demographics, areas of residence, lifetime cardiac events, and noncardiac medical history. The majority of patients seen during the study period had moderate or complex anatomy. Not surprisingly, the most common cardiac comorbidity in all groups was arrhythmia. Specific cardiac anatomy by lesion is outlined in [Supplemental Table S1](#). For patients with simple anatomy, bicuspid valve was the most common primary anatomy (n = 26; 10%), followed by restrictive ventricular septal defect (n = 7; 3%). Repair of tetralogy of Fallot was the most common moderately complex lesion (n = 27; 10%), with patients palliated by Fontan circulation accounting for the majority of complex lesions (n = 21; 8%; [Supplemental Table S1](#)).

Cardiac events/complications

For lifetime risk of cardiac events, the most common events were arrhythmias (15%), syncope (8%), implantable

cardiac defibrillator/pacemaker intervention (8%), and congestive heart failure (6%; [Table 1](#)). In our sample, patients with complex anatomy had the highest incidence of congestive heart failure, atrial fibrillation, and syncope. Noncardiac comorbidities were seen frequently throughout each group, with mood disorder or anxiety being the most common (12%), as well as hypertension (10%), diabetes (7%), self-reported learning difficulties (6%), and cerebrovascular accidents (5%).

Health care resource utilization

Health care resource utilization by patient age and anatomy complexity over the study period is outlined in [Figure 2](#). There was a significant difference in use of cardiac imaging among anatomy-complexity groups, with the complex-anatomy group undergoing 120 imaging encounters per 100 person-years, the moderate-anatomy group having 98, and the simple-anatomy group having 81 ($P < 0.001$). Echocardiography was the most common imaging modality throughout the complexity groups, performed at a rate of 48 per 100 person-years ([Supplemental Figure S2](#)). Patients with complex anatomy had more-frequent clinic visits per 100 person-years (104) than those with moderate (86) or simple (71) anatomy ($P < 0.001$; [Fig. 1](#)). There was no significant difference in number of cardiorespiratory-related emergency room visits across complexity groups. As shown in [Figure 2](#), patients over the age of 50 years with complex heart disease spend more than double the number of inpatient days compared to any other age group or anatomy-complexity group. The recommended amount of total cardiac imaging increased steadily with age in patients with complex heart anatomy, and it was consistently higher than that for simple or moderate anatomies across age groups.

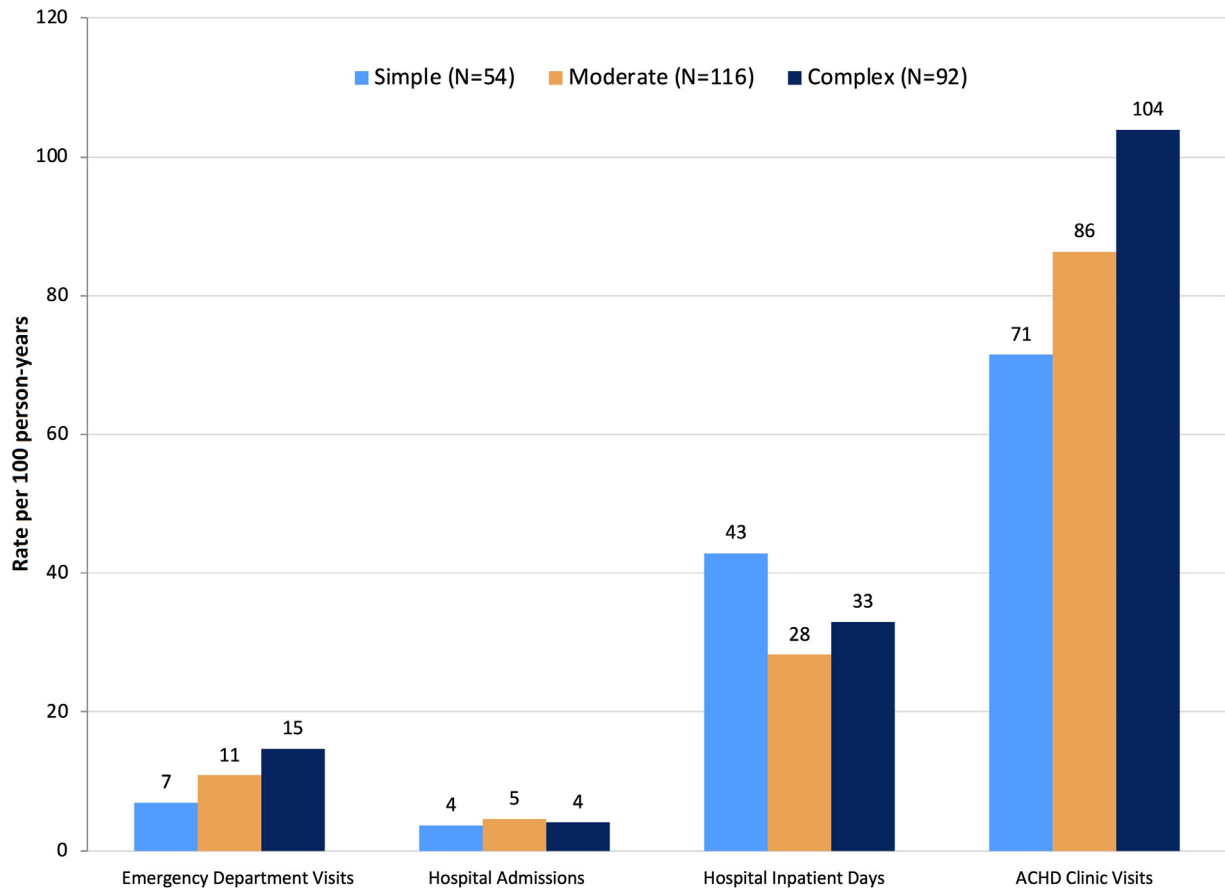


Figure 1. Health care utilization by anatomy complexity—rate of health care contacts by adult congenital heart disease (ACHD) complexity per 100 person-years.

Required out-of-province care

The need for medical services or procedures for specialized ACHD care not available in our regional centre/province was identified across complexity groups. Overall, 10% of patients required out-of-province specialized ACHD care within the study period, most of whom had complex anatomy. Only patients with moderate (8%) or complex (20%) anatomy required specialized ACHD interventional or surgical care out of province. All ACHD patients with simple anatomy were managed with the resources available in our province.

Discussion

Adults with congenital heart disease outnumber the pediatric population by a ratio of 2:1, and the adult population continues to grow steadily.^{5,9} Understanding the characteristics of the ACHD population is essential in planning resource allocation and meeting the growing needs for specialized cardiology care for these patients. Small- to moderate-sized ACHD care centres are a growing and integral part of ACHD care for many patients. Our experience as a moderately sized regional centre is representative of the limitations of care outside of major/well established ACHD centres and may provide insight into the patient care needs for other centres with similar sizes and resources.

Lifetime cardiac complications were frequently seen in the study population, especially in the complex-anatomy group. The most common cardiac event identified in the current study population was arrhythmia, with a high incidence across complexity categories. This finding is consistent with other Canadian data suggesting that the most common causes for cardiac hospitalizations are supraventricular arrhythmias, non-specific arrhythmias, chest pain, and congestive heart failure.⁹ Congestive heart failure was seen in our complex population also, with 11% of the complex group requiring at least one hospitalization. Interestingly, endocarditis was not strongly associated with underlying complex anatomy. The results demonstrated a higher lifetime incidence of endocarditis in patients with simple lesions. Although the precise reasons for this finding remain unclear, it is likely related to the small sample size. Other plausible explanations are an increased use of antibiotic prophylaxis in moderate and complex patients, or a group of patients with “simple” lesions that have presented to specialized care due to a more complicated medical course, thus enriching the ACHD clinic with more unwell patients that have simple lesions.

Implantable cardiac devices were seen occasionally in our cohort, with 8% having a permanent pacemaker or implantable cardiac defibrillator. This proportion was higher in patients with moderate and complex disease, both with 10%, compared to 2% of patients with simple disease. It is expected

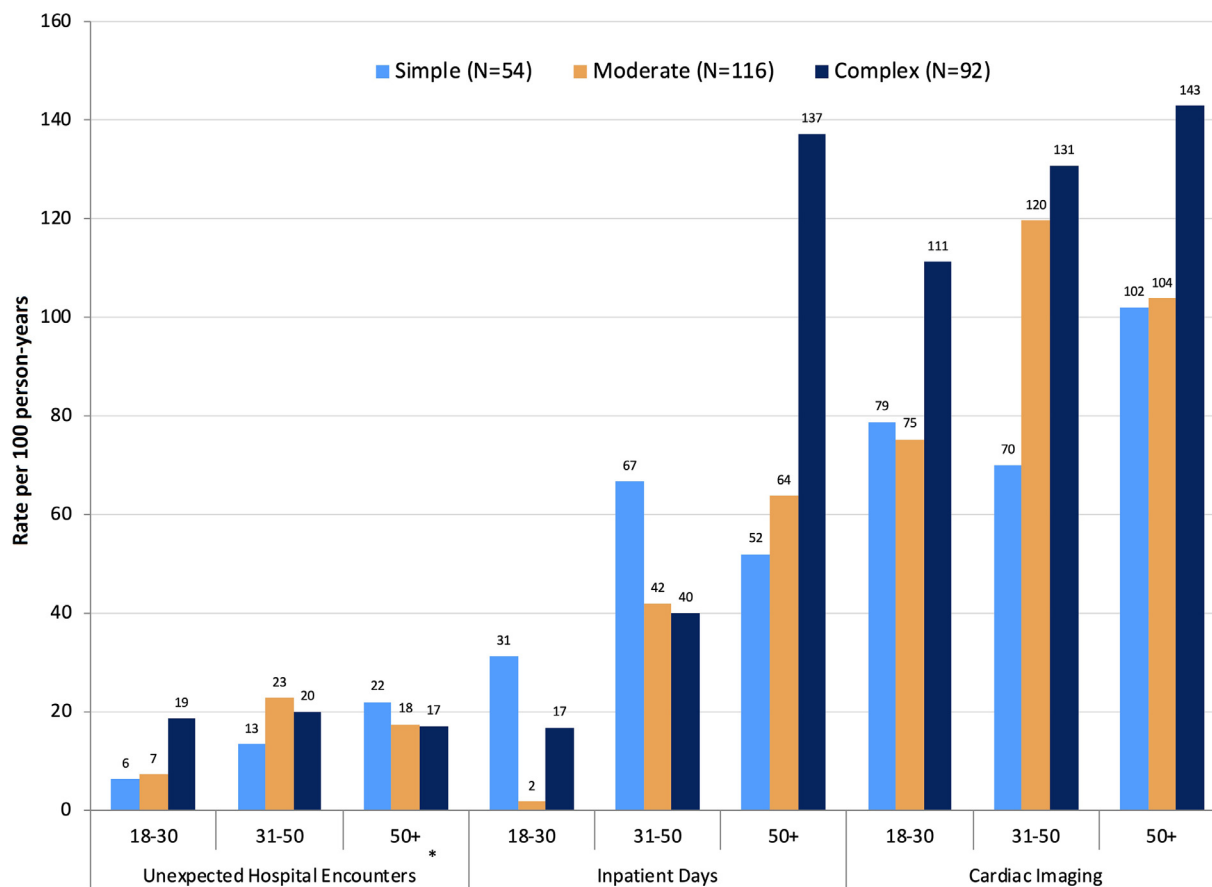


Figure 2. Health care utilization by age and anatomy complexity—summary of health care contacts by adult congenital heart disease complexity and age in 100 person-years. *Unexpected hospital encounters is defined as the sum of cardiorespiratory-related emergency department visits and hospital visits.

that these patients will require additional ongoing specialized care at pacemaker clinics, will need invasive battery-pack changes, and are at an increased risk of infection and complications related to device malfunctions and replacements, resulting in increased health care utilization over patients' lifetimes. The overall increase in medical complications and health care resource utilization could not be well characterized from the short follow-up time period of this study.

Previous work has demonstrated that the rate of hospitalization was higher in ACHD patients with complex compared with simple lesions.⁵ In our study, we found this to be the case in the young population. Patients with complex disease between the ages of 18 and 30 years had 3 times more unexpected hospital encounters compared to patients with simple disease, a rate slightly lower than the rate for patients with moderate disease (Fig. 2). Furthermore, patients of all ages with complex disease had a higher degree of ACHD clinic visits than did patients with simple or moderate disease. Interestingly, this difference was not reflected in longer inpatient hospital stays in patients with complex disease compared to other groups. Figure 1 demonstrates that patients with simple disease had longer inpatient stays. Specifically, the longer hospital stay in the simple group was seen in the 18-30-year and 31-50-year age groups compared to patients with moderate or complex disease (Fig. 2). This difference might be explained in part by the fact that patients

with moderate or complex disease were significantly more likely to be sent out of province for higher-level care not currently available in our province. Furthermore, the higher incidence of endocarditis found in the simple-disease group may require longer hospital stays than common causes of hospitalizations for complex-disease patients, such as congestive heart failure and supraventricular arrhythmias, thus masking the potential difference between groups. When patients with simple lesions with endocarditis were excluded from the inpatient stay analysis, complex patients did in fact have longer inpatient stays than did those with moderate or simple lesions. This difference was most pronounced in patients between the ages of 18 and 30 years (see Supplemental Table S2).

Patients aged 31-50 years with simple congenital heart disease had longer hospital stays than any other complexity group in that age range, whereas patients aged 50 years and older with complex congenital heart disease had more than double the length of hospital stay than both the moderate- and simple-complexity groups in that age range (Fig. 2). This finding has implications for the future aging ACHD population and health care system. As the population ages, we would anticipate an increased need for inpatient care in the ACHD population, especially in the complex group. This prediction is consistent with data showing increasing rates of admission for patients with ACHD who are over the age of 30 years,

compared to younger groups,¹ and an overall increased admission rate of 4% per year in Canada.¹⁰ An increase in novel and aggressive surgical repairs for congenital disease in infancy has resulted in more children with complex disease surviving to adulthood than in previous decades.¹¹ As this growing cohort enters adulthood, they are at an increased risk of complications and morbidity in young adulthood and will require increasing health care resources.

Cardiac interventions were relatively frequent in this cohort. Some of the interventions were provided in Manitoba; however, approximately 10% of the cohort (8% of moderate and 20% of complex cases) required out-of-province specialized cardiac procedures, such as congenital heart surgery or catheter-based interventions. This number will likely increase as more patients are referred, the current population ages, and new interventions become available in large specialized surgical centres. In Canada, expertise in ACHD interventional and surgical procedures is focused primarily in 5 major Canadian centres spread across the country (Vancouver, Edmonton, Toronto, Montreal, and Halifax). Such regionalization has the benefit of greater levels of health team experience and expertise. However, it potentially poses financial and social stresses on the system, and patients and their families, who must travel to have access to required specialized ACHD procedures. These stressors include costs of travel, accommodations, and food, as well as loss of income, among others. The financial and patient costs of out-of-province care for specialized procedures has not been well characterized in Canada. Future research may help better clarify the direct and indirect cost of travel for ACHD procedures and how this may expand with the growing complexity of the ACHD population.

Limitations

There are a few important limitations in the current study, and our results need to be taken in context. Our data were collected from an electronic patient record portal that is limited to hospitals and health centres across the province that utilize it. Details on out-of-province hospitalization and cost could not be captured by the current study. Some smaller, rural health centres do not utilize this electronic patient record, and so any events/presentations to these centres were not be captured. Unexpected hospital encounters, such as emergency department presentations or hospitalizations, may have been underestimated when patients visited smaller or out-of-province health centres. However, given that the majority of cardiac investigations for ACHD occur primarily in the major provincial hospitals, we believe the current data provide a reasonable estimate of the true utilization of health resources and access to care.

In addition, the accuracy of the information in the electronic patient record is dependent on the comprehensiveness and accuracy of information entered by health care providers. There were some instances in which information was unavailable, incomplete, or unclear, which could potentially have led to underestimation of utilization of health care resources. Furthermore, noncardiac comorbidities were mainly self-reported, potentially affecting their accuracy. The current study sample was relatively small, which may limit the ability to confidently generalize the findings to other ACHD regional

centres; however, we believe we have captured a reasonable sample of our population, and the data provide a good assessment of their resource use. Also, the 1-year period used to sample the population may have underestimated the true proportion of patients with simple disease, as they are usually seen in clinics at intervals greater than a year, thereby inflating the proportion of patients with moderate and complex disease in our sample.

Finally, the study assumes that all subjects were followed by the clinic for the entire 5-year period, which was true in almost all cases. An exception is young adults transitioning from pediatric to adult care. Thus, the number of clinic visits in this subpopulation may have been underestimated. Fortunately, most lifetime diagnostic imaging and unexpected health encounters would have been captured in the provincial electronic patient records and therefore included in the study.

Conclusions

Adult patients with congenital heart disease require lifelong specialized health care and are at increased risk of complications. This population is expected to increase, and with it, so will the health care resources required for their care. We demonstrate imaging, clinic, and hospital resource utilization at a regional centre of moderate size, with the highest rate of use in the older patients with complex disease. This information is the foundation of planning for adequate hospital and human resource allocation, in order to provide the accepted standard of care for the growing ACHD population.

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Disclosures

The authors have no conflicts of interest to disclose.

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Supplementary Material

To access the supplementary material accompanying this article, visit *CJC Open* at <https://www.cjopen.ca/> and at doi:10.1016/j.cjco.2021.05.005.