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Patient factors and geographic barriers influencing excess time between paediatric and adult CHD care

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Abstract

Introduction: Over 90% of children with CHD survive into adulthood and require lifelong cardiology care. Delays in care predispose patients to cardiac complications. We sought to determine the time interval to accessing adult CHD care beyond what was recommended by the referring paediatric cardiologist (excess time) and determine risk factors for prolonged excess time. *Materials and Methods:* Retrospective cohort study including all patients in the province of Alberta, Canada, age 16–18 years at their last paediatric cardiology visit, with moderate or complex lesions. Excess time between paediatric and adult care was defined as the interval (months) between the final paediatric visit and the first adult visit, minus the recommended interval between these appointments. Patients whose first adult CHD appointment occurred earlier than the recommended interval were assigned an excess time of zero. *Results:* We included 286 patients (66% male, mean age 17.6 years). Mean excess time was 7.9 ± 15.9 months. Twenty-nine (10%) had an excess time > 24 months. Not having a pacemaker ($p = 0.03$) and not needing cardiac medications at transfer ($p = 0.02$) were risk factors for excess time >3 months. Excess time was not influenced by CHD complexity. *Discussion:* The mean delay to first adult CHD appointment was almost 8 months longer than recommended by referring paediatric cardiologists. Not having a pacemaker and not needing cardiac medication(s) were risk factors for excess time > 3 months. Greater outpatient resources are required to accommodate the growing number of adult CHD survivors.

Major advances in the management of children with CHD have evolved over the past few decades. Consequently, over 90% of children with CHD reach adulthood[1] and the population of patients with adult CHD is growing exponentially.[2] This emerging survivor population has complex needs and are at risk of substantial cardiac morbidity and mortality in early-to-mid adult years.[3] Unfortunately, many adolescents and young adults with CHD have limited knowledge about their heart[4] including the need for ongoing follow-up in specialist adult CHD centres, and only a minority of paediatric cardiac centres offer dedicated services/programs to facilitate this period of transition.[5] Furthermore, many young adults have a lapse in cardiology care lasting greater than two years after graduating from a paediatric cardiac center.[6] Failure to attend an adult CHD clinic may result in late recognition of cardiac morbidity, and delays in attending the first adult CHD appointment of greater than two years has been associated with the need for surgical or catheter re-intervention within the next 6 months.[6]

Whether or not a young adult attends an adult CHD clinic is a crude outcome variable. Rather, the time between the final paediatric visit and the first adult CHD visit, beyond what was recommended by the referring paediatric cardiologist, is a variable that captures not only whether a patient was seen in an adult CHD clinic but also the time delay, if any, in arriving there. The degree of "excess time" experienced by CHD patients has not previously been described in the literature. Therefore, the objectives of this study were to: describe the excess time to adult CHD care and determine the patient and system factors that influence excess time.

Materials and methods

Study design and eligibility criteria

We conducted a retrospective cohort study of all patients with moderate or complex CHD, as defined by the 32nd Bethesda Conference,[7] having a final paediatric outpatient cardiology clinic visit between January 2005 and February 2013 and being between 16 and 18 years of age at their last paediatric cardiology visit. Patients with simple CHD were not included, as the implications

for excess time on their long-term morbidity and mortality are not the same as those with moderate to severe CHD. The age range of 16–18 at the final paediatric appointment was used, as the age of transfer is dictated by the provincial health care system, and paediatric cardiologists do not typically see patients beyond 18 years of age. Patients were excluded if they were known to have relocated outside the catchment area of a study site or had a heart transplant.

Study setting

The study was conducted at both paediatric cardiology sites within the province of Alberta: The Stollery Children's Hospital in Edmonton and the Alberta Children's Hospital in Calgary. Adult CHD care is also divided between two locations: the Mazankowski Alberta Heart Institute in Edmonton and the Peter Lougheed Center in Calgary. In Edmonton, the paediatric and adult CHD centre are both on the University of Alberta Campus, whereas in Calgary the paediatric and adult CHD centres are 15 km apart. Neither adult CHD centre offered outreach clinics during the study window; all adult CHD appointments were in Edmonton or Calgary. The adult CHD clinics routinely contacted patients to arrange the first appointment, rather than relying on patients to do so. Paediatric and adult CHD sites had separate and independent medical records. No formal transition programme was in place in either centre during the study window. Community-based paediatric cardiologists were also contacted regarding appointment dates and their referrals to adult CHD providers.

Outcome variables

The primary outcome was the "excess time" to accessing adult CHD care. Excess time between paediatric and adult CHD care was defined as the time interval (in months) between the final paediatric appointment and the first adult CHD visit, subtracted by the recommended time interval between these visits. For example, if the time between the final paediatric visit and first adult CHD visit was 18 months, but the paediatric cardiologist recommended this be 12 months, the excess time was 18–12 = 6 months. Patients whose first adult CHD appointment occurred earlier than the recommended interval were assigned an excess time of zero.

Data collection

The paper and electronic medical records of eligible patients were reviewed by one primary reviewer at the Edmonton site and one of two primary reviewers at the Calgary site. Data collected from each chart are shown in Table 1. Co-morbid chronic health conditions were defined as any health condition of at least 3 months' duration that required ongoing care by a physician or nurse practitioner and/or were likely to influence morbidity or mortality. Additional data collected included: the date of the final and second-to-last paediatric cardiology appointments, the recommended follow-up interval to the first adult CHD appointment, and dates of the first and subsequent adult CHD visits.

When the anatomical severity of a CHD diagnosis could not be clearly defined by the Bethesda Conference guidelines, a patient was assigned as having moderate or complex CHD by the Principal Investigator at each site. Social risk factors were ascertained from the information documented on the paediatric transfer letters written by paediatric cardiologists; social workers did not routinely meet with patients. Social history was taken from the adult CHD letters only if it was clearly documented that these behaviours were in practice at the time the patient was under paediatric care. In the Calgary cohort, the address used to calculate the distance between their home and care sites was based on the location of the adult CHD clinic. In the Edmonton cohort, the paediatric and adult clinics were located at the same site. Unless a different address was listed on the paediatric referral letter, it was assumed that the patient did not move residences at the time of transfer.

Table 1. Predictor variables.

Patient versus system	Variable
Patient factors	CHD complexity: Moderate vs. severe
	Cardiac surgical procedure in childhood (Yes/No)
	Cardiac catheterisation during adolescence, age 13–17 (Yes/No)
	*Driving distance from home to adult CHD site (km)
	Co-morbid chronic health conditions during childhood (Yes/No)
	Documented risk-taking behaviours** during adolescence (Yes/No)
	Pacemaker or defibrillator (Yes/No)
	Taking cardiac medication(s) at final paediatric appointment (Yes/No)
	Taking warfarin at final paediatric appointment (Yes/No)
System factors	Centre 1 versus Centre 2
	Recommendation for adult CHD follow-up (Yes/No)

*Distance from the patient's home to care centres was calculated as the shortest driving distance identified by Google maps.
**Risk taking behaviours in paediatric care included: smoking, street drug use, alcohol consumption, sexual activity, tattoos/piercings.

For some patients, the recommended first adult CHD appointment/follow-up interval in the final paediatric appointment letter was either not explicitly provided, given as an interval range of two time points, or provided in qualifying terms. When a specific time was not provided, the interval in months between the second-to-last and final paediatric appointments was used as the recommended follow-up interval. In the instance when a time range was recommended (e.g., "24–36 months"), the later time point was used to be conservative (i.e., 36 months). When qualifying terms were used, this often correlated to a seasonal cut-off, such as "Summer." In this instance, the final month of the season, for example, September being the transition between Summer and Fall was used. A single reviewer made this call for all such cases to ensure consistency. Rarely, when the referring paediatric cardiologist did not recommend a time interval to first adult CHD appointment, and there were no second-to-last paediatric letter on file, the recommended follow-up intervals defined by anatomical lesion severity in the Bethesda Conference[7] were used for the most significant heart lesion.

Continuous variables were summarised as mean with standard deviation or median and interquartile range, as appropriate. Binomial logistic regression models were used to assess the effect of the predictor variables and the outcome variable of binary excess time (whether a patient exceeded pre-specified threshold of excess time). First, univariate models were created. Then, variables with $p < 0.25$ were explored further in the multivariable binomial logistic regression to create the parsimonious model for each binary excess time $\geq$ 3 months versus $<$ 3 months. The log-rank

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test was used to examine between-group differences in excess time. Variables with $p < 0.25$ were used in multivariable Cox regression models to evaluate their combined effect of predictor variables and the outcome variable of continuous excess time. Statistical analysis was conducted using SAS Version 9.4 (SAS Institute Inc., Cary, NC, USA) software. Ethics approval was obtained from the University of Alberta Health Research Ethics Board (Pro00041428) and the University of Calgary Ethics Board (REB15-1604).

Results

Two hundred and eighty-six patients (66% male, mean age 17.6 ± 0.7 years at last paediatric appointment) were included. During the study follow-up time, 282 of 286 patients (98.6%) had an adult CHD clinic appointment. Four patients without an adult CHD appointment were censored at the end of the follow-up period (at the chart extraction date). The mean age at the first adult CHD appointment was 19.3 ± 1.5 years. Second adult CHD appointments occurred in 233 patients (81.5%). The median duration of follow-up, from last paediatric appointment to final review of medical record, was 67 months (interquartile range 42.2–88.3). Patient characteristics are summarised in Table 2.

The time to the first adult CHD appointment exceeded the recommended follow-up interval in 177 patients (61.9%). The mean excess time between the final paediatric visit and the first adult CHD visit was 7.9 ± 15.9 months. Median excess time was 1.7 months with range 0–117.5 months and interquartile range 0–8.4 months. Twenty-nine patients (10.1%) had an excess time greater than 2 years. Figures 1 and 2 highlight the distribution of excess time.

Table 3 portrays the univariate Log rank test. Pacemaker/defibrillator, use of cardiac medication at the final paediatric visit, warfarin use, and driving distance from the adult CHD centre were statistically significant variables (p value < 0.05). On multivariable analysis, a recommendation for adult CHD follow-up in the final paediatric letter, presence of a pacemaker or defibrillator, and use of cardiac medications were each associated with a greater likelihood of having had an adult CHD visit at any given time (Table 4, Fig. 3a, b).

Excess time was divided into two time periods: ≤ 3 months and>3 months, as the latter likely represents a clinically significant delay in accessing care. In this analysis, 121 patients (42.3%) had an excess time to adult CHD care > 3 months. Multivariable logistic regression showed that the presence of a pacemaker/defibrillator ($p = 0.03$) and cardiac medication use during the last paediatric clinic visit ($p = 0.02$) were protective against excess time to access adult CHD care>3 months (Tables 5 and 6). Patients with a pacemaker or defibrillator were 69% less likely to have excess time>3 months relative to those without a pacemaker or defibrillator, and those on cardiac medications at the final paediatric visit were 51% less likely to have an excess time>3 months, relative to those not on cardiac medications.

Discussion

This study evaluated delays in attending first adult CHD appointments among young adults with moderate or complex CHD who had been managed at one of two paediatric cardiology programs in the province of Alberta, Canada. Key findings of this study include: (1) the great majority of patients had at least one adult CHD appointment in the context of a long duration of follow-up, yet (2) most patients (61.9%) had a delay to their first adult CHD appointment, with 42.3% having a delay > 3 months and 10% experiencing a delay > 2 years beyond what had been recommended; and (3) not having a pacemaker or defibrillator was a risk factor for excess time > 3 months, as was not needing cardiac medications at the time of the final paediatric appointment.

Although widely recognised as a vulnerable stage in CHD lifespan care,[8,9] there is a paucity of data regarding effective strategies to help patients successfully traverse the bridge between paediatric and adult care. This problem is not isolated to cardiology but extends across other chronic paediatric conditions as well.[10] Therefore, quantifying the gap in care and identifying risk factors, both patient- and system-based, is an essential step to addressing this problem. Previously identified barriers to a successful transition include lack of knowledge regarding the need for adult CHD follow-up,[11,12] feeling well,[13] an inability to find specialised providers, and lack of health care insurance.[13] Patients more likely to become lost to follow-up include males,[14] those followed outside of University centres,[14] and lower socio-economic status.[15] This study adds to the existing literature by identifying risk factors for longer excess time to adult CHD care, enabling clinicians to

Table 2. Patient characteristics.

Variable		N	Percent
Age (mean ± SD) at final paediatric appointment		17.6 ± 0.7	
Age (mean ± SD) at first adult CHD appointment		19.3 ± 1.5	
Male gender		188	65.7
Adult CHD follow-up recommended in final paediatric letter		253	88.5
CHD Complexity	Moderate	197	68.9
	Complex	89	31.1
Primary CHD Diagnosis	Tetralogy of Fallot	50	17.5
	Coarctation of the aorta	38	13.3
	Atrioventricular septal defect	34	11.9
	Transposition of the great arteries	29	10.1
	s/p Fontan palliation	21	7.3
	Other	114	39.9
Previous cardiac surgery		246	86.0
Previous cardiac catheterisation (N = 270)		152	56.3
Documented co-morbid chronic health condition during childhood (N = 283)		201	71.0
Risk-taking behaviour**	No / Not documented	196	68.5
	Yes	90	31.5
Pacemaker / defibrillator (N = 273)		31	11.4
Cardiac medication use during the last paediatric clinic visit (N = 283)		80	28.3
Warfarin (Coumadin) use		19	6.6
Centre	Calgary	208	72.7
	Edmonton	78	27.3
Median driving distance between home and adult CHD centre		25 km [IQR 14–114 km]	

IQR = interquartile range; SD = standard deviation.
*Denominator = 286 unless otherwise specified.
**Risk-taking behaviours in paediatric care included: smoking, street drug use, alcohol consumption, sexual activity, tattoos/piercings.

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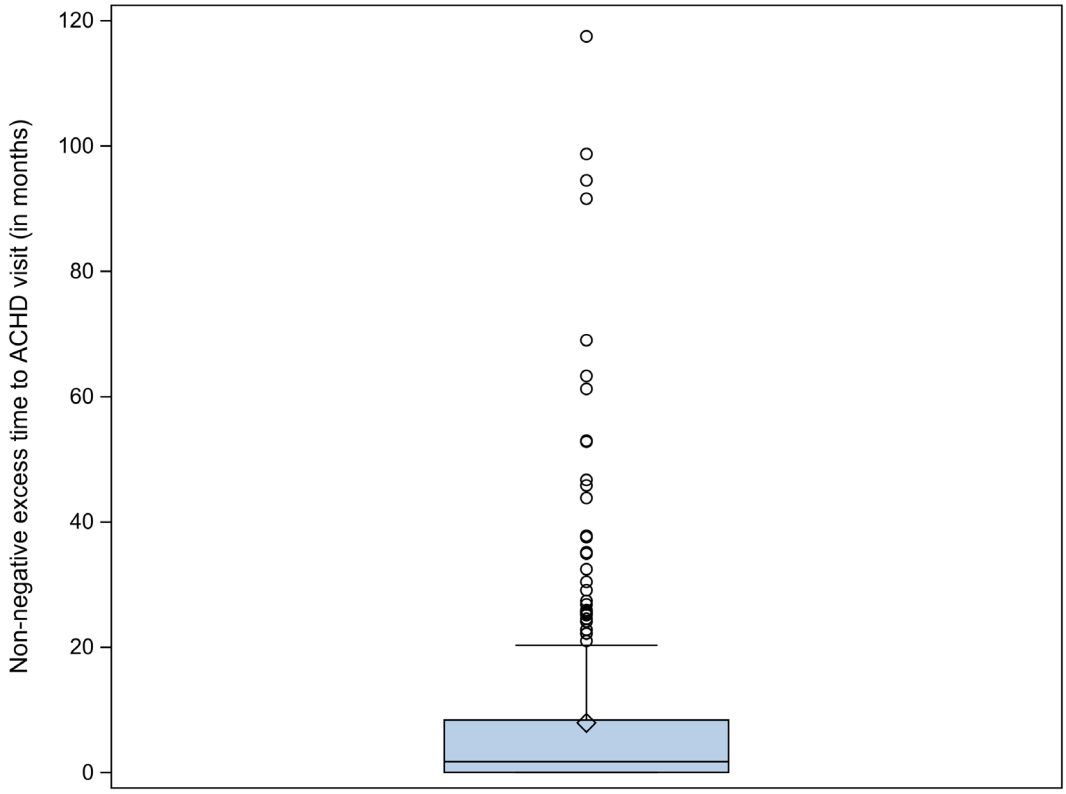

Figure 1. Distribution of excess time.

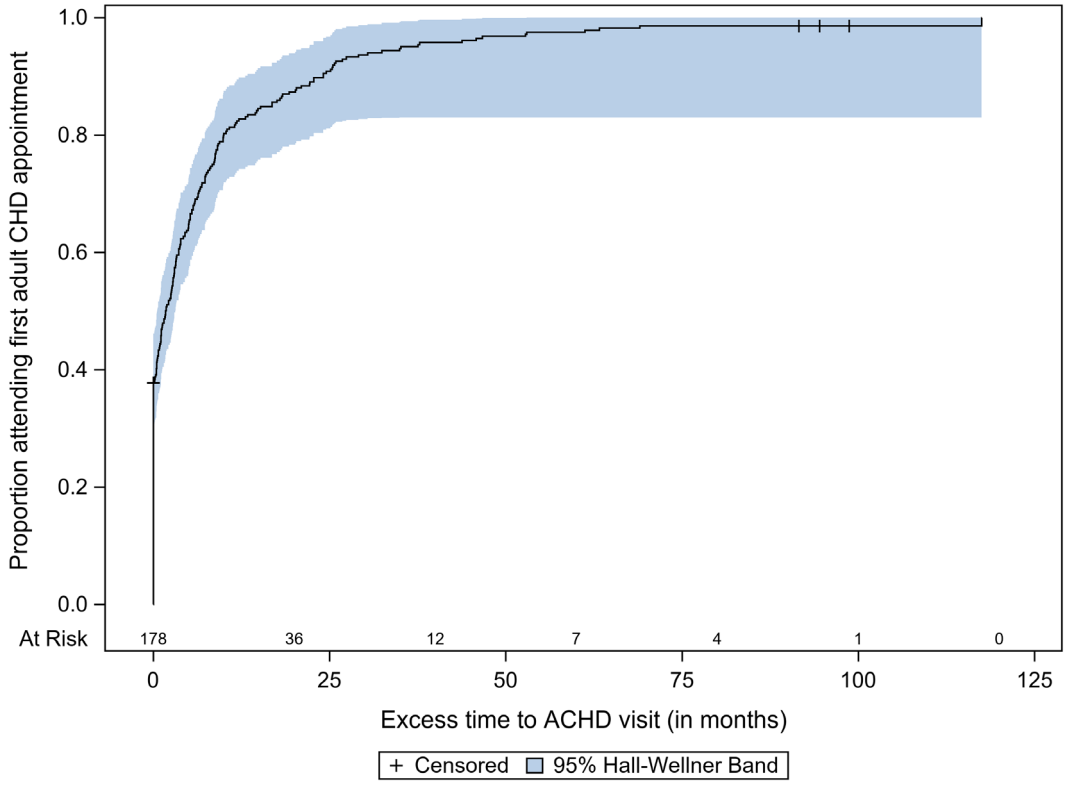

Figure 2. Time to first adult CHD appointment as a function of excess time in the full study cohort.

implement strategies to mitigate this problem. For example, emphasising the need for lifelong specialised cardiology follow-up and informing patients about the recommended time interval to the first adult CHD appointment will increase awareness among adolescents graduating from paediatric care. Likewise, electronic medical records can be used to implement warnings to providers when a patient referred to adult CHD care is assigned an appointment date that is beyond the recommended time.

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Table 3. Excess time Univariate log-rank.

Variable	p-value from Logrank test
Adult CHD follow-up recommended in final paediatric letter (Yes versus No)	0.08
CHD Complexity (Moderate versus Complex)	0.93
Previous Cardiac Surgery (Yes versus No)	0.21
Previous Cardiac Catheterisation (Yes versus No)	0.55
Documented co-morbid chronic health condition during childhood (Yes versus No)	0.89
Risk taking behaviour (Yes versus No/Not documented)	0.95
Pacemaker / defibrillator (Yes versus No)	0.001
Cardiac medication use during the last paediatric clinic visit (Yes versus No)	0.003
Warfarin (Coumadin) use (Yes versus No)	0.02
Centre (Calgary versus Edmonton)	0.61
Driving distance from home to adult CHD clinic	0.02

Table 4. Multivariable cox model.

		95% CI for the HR		
Variable	Hazard ratio	Lower limit	Upper limit	p-value
Adult CHD follow-up recommended in final paediatric letter	1.44	1.01	2.08	0.047
Pacemaker or defibrillator	1.61	1.25	2.08	0.0003
Cardiac medication use during the last paediatric clinic visit	1.35	1.05	1.72	0.018

The presence of a pacemaker or defibrillator resulted in a device clinic playing a part in patient's care at both study sites. However, this study did not track appointments in device clinics, and therefore the shorter excess time in this group cannot be accounted for based on being seen in device clinic alone. The presence of a pacemaker or defibrillator may help young adults acknowledge that they require lifelong cardiology follow-up and having an additional care team (in device clinic) may further reinforce that message.

The use of cardiac medication at the time of the last paediatric appointment likely serves as a daily reminder to patients that they are not cured, creating awareness of the need for lifelong follow-up. From a practical perspective, the need for medication renewals or new prescriptions may have necessitated that patients see their new adult CHD providers earlier rather than later. Patients on cardiac medications may also have higher residual haemodynamic burden and/or symptoms that prompt more timely arrival in the adult CHD clinic.

We hypothesised that having paediatric and adult CHD care in the same vicinity may facilitate transition and transfer of care, resulting in less excess time. Previous reports have highlighted patient anxiety about not knowing where to go for their first appointment, or how to get there,[16] and the benefit to patients when introduced in person to the adult clinic in advance of their first appointment.[17] However, we did not find a difference in excess time between the Calgary and Edmonton sites, despite the co-location of paediatric and adult CHD programs in Edmonton, compared to the separate paediatric and adult sites, 15 km apart, within Calgary. It appears that patient factors and other system factors are more important determinants of timely arrival in the adult CHD clinic.

This is the first study to describe and report excess time to adult CHD care. Previous studies have described lapsed time since the final paediatric appointment in absolute duration.[6] However, a lapsed time of 36 months for a patient with a simple lesion (e.g., bicuspid aortic valve with mild valvar aortic stenosis and a recommended time of 24 months and excess time of 12 months) is likely very different from a patient having a complex lesion and the same lapsed time (e.g., patient with a Fontan circulation and moderate-severe ventricular dysfunction with recommended time of 6 months and excess time of 30 months). The latter patient is much more likely to deteriorate and/or require an intervention. The longer excess time for the patient with a Fontan circulation captures the significance of the delay to first adult CHD appointment, whereas absolute lapsed time does not.

More than one-third of patients had a negative excess time (i.e., were seen in an adult CHD clinic earlier than recommended). This may have reflected sufficient adult CHD clinic capacity at the time of referral, or patients reaching out and seeking earlier appointments due to new symptoms or other concerns. To identify a subgroup with potentially significant delays, we chose an excess time of≥3 months for the logistic regression analysis. However, this is a somewhat arbitrary threshold. It is beyond the scope of this study to determine the excess time beyond which patients experience avoidable morbidity related to late diagnosis of new cardiac complications.

This study has several limitations inherent in the retrospective design. Documentation of adolescent risk-taking behaviours in the medical record was incomplete for most patients, and lack of documentation does not equate to the absence of risk-taking behaviours. Delays in data collection and analysis by the team were significant, largely due to challenges identifying the cohort of

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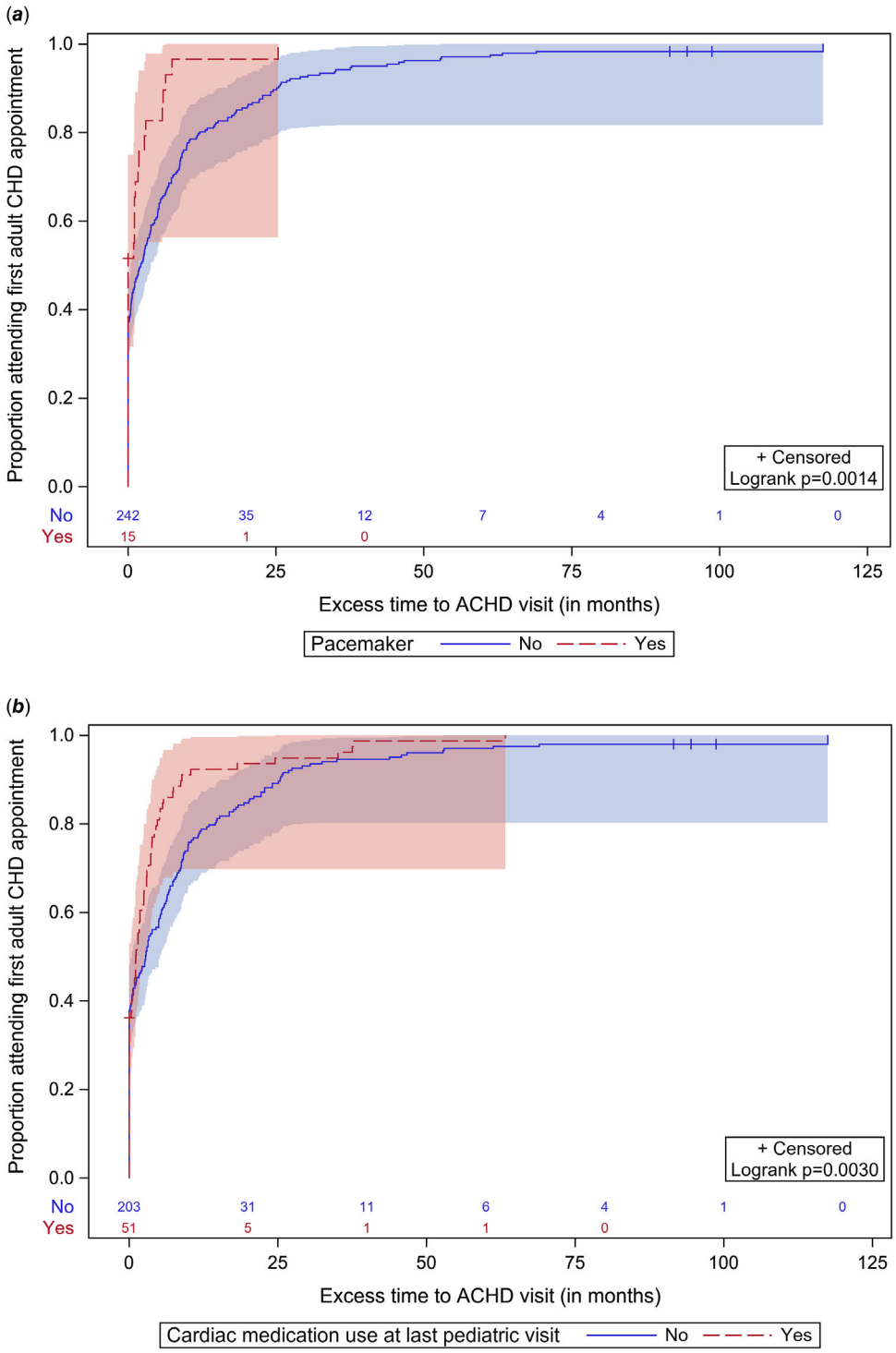

Figure 3. Patients with a pacemaker or defibrillator (***a***) had a shorter time to first adult CHD appointment as did patients on a cardiac medication at the time of their last paediatric cardiology clinic visit (***b***).

patients that had graduated from one of the participating paediatric sites, and the team's careful follow-up with all adult CHD providers in the province, including those in community-based practice, to ensure data completeness. This had the benefit of a long follow-up time interval (median 67 months), but it is possible that the duration of excess time in this study under- or over-estimates the excess time currently faced by patients and health care providers. The number of patients having a pacemaker or defibrillator was relatively low (n = 15), so caution should be applied in interpreting that data. Recommended follow-up time by the referring paediatric cardiologist was not standardised and is likely variable from one provider to the next. Excess time may have been due to missed appointments[18] or lack of adult CHD clinic capacity to schedule appointments, but our data sources did not allow that distinction to be made reliably. Data on socio-economic status was not available to the study team. The excess time may be higher in countries without universal access to healthcare,[19] though the risk factors identified in this study are at the patient

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Table 5. Logistic regression for excess time > 3 months: univariable model.

Variable	Coefficient estimate	95% CI for the estimate		p-value
		Lower limit	Upper limit	
Adult CHD follow-up recommended in final paediatric letter (Yes versus No)	0.75	0.36	1.56	0.45
CHD Complexity (Moderate versus Complex)	0.98	0.59	1.62	0.93
Previous Cardiac Surgery (Yes versus No)	0.88	0.45	1.73	0.71
Previous Cardiac Catheterisation (Yes versus No)	0.71	0.44	1.16	0.17
Documented co-morbid chronic health condition during childhood (Yes versus No)	0.88	0.52	1.48	0.63
Risk taking behaviour (Yes versus No/Not documented)	1.06	0.64	1.76	0.81
Pacemaker / defibrillator (Yes versus No)	0.23	0.09	0.62	0.004
Cardiac medication use during the last paediatric clinic visit (Yes versus No)	0.47	0.27	0.81	0.007
Warfarin (Coumadin) use (Yes versus No)	0.47	0.16	1.33	0.15
Centre (Calgary versus Edmonton)	1.08	0.63	1.82	0.79
Driving distance from home to adult CHD clinic				0.12
60 – 90 km versus less than 52 km	0.98	0.29	3.32	0.52
100 – 200 km versus less than 52 km	0.36	0.16	0.84	0.048
More than 210 km versus less than 52 km	0.77	0.39	1.51	0.84

Table 6. Logistic regression for excess time > 3 months: multivariable model.

Variable	Coefficient estimate	95% CI for the estimate		p-value
		Lower limit	Upper limit	
Pacemaker / defibrillator (Yes versus No)	0.31	0.11	0.87	0.03
Cardiac medication use during the last paediatric clinic visit (Yes versus No)	0.49	0.27	0.91	0.02

Warfarin use, previous cardiac catheterisation, and driving distance from home to adult CHD clinic were not statistically significant.
Above are estimates for combined effect of presence of pacemaker/defibrillator and cardiac medication use during the last paediatric clinic visit on whether the excess time to adult CHD visit is>3 months.

level, not the health system level, so these risk factors may apply in other jurisdictions. The excess time may be higher in centres where patients rather than providers are responsible for initiating the first adult CHD appointment.

In conclusion, excess time between paediatric and adult CHD care is a novel variable that captures not only whether a patient is seen in an adult CHD program, but the time interval to the first adult CHD appointment, relative to what had been recommended by the referring paediatric cardiologist. Mean excess time was almost 8 months, with 42% of patients having an excess time > 3 months. Having a pacemaker or defibrillator, use of cardiac medication, and documentation in the medical record that adult CHD follow-up is recommended were associated with timelier first adult CHD appointments. Excess time can be used by adult CHD programs for quality improvement purposes to track whether they are able to accommodate graduates from paediatric care within the time interval recommended by referring paediatric cardiologists.

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Competing interests. None.

Ethical standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the Helsinki declaration of 1975, as revised in 2008, and have been approved by the Health Research Ethics Boards at the University of Alberta and the University of Calgary.

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