Children and Adults With Congenital Heart Disease Lost to Follow-Up
Who and When?

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Background—Many patients with congenital heart disease (CHD) require lifelong care. However, the duration of cardiology follow-up in children and adults with CHD is unknown. We sought to determine the proportion of children and young adults with CHD receiving outpatient cardiology care and to identify predictors of lack of follow-up.

Methods and Results—The study population consisted of individuals born in 1983 and alive at age 22 years who were diagnosed with CHD in Quebec, Canada, before 6 years of age (n=643). Patients and outpatient visits were identified with the use of the provincial physician's claims database. Three age groups were examined for the presence of outpatient cardiology follow-up: 6 to 12, 13 to 17, and 18 to 22 years. CHD lesions were classified as severe (n=84; 13%), simple shunts (n=390; 61%), and "other" lesions (n=169; 26%). Failure to receive cardiac follow-up after the 6th, 13th, and 18th birthday occurred in 28%, 47%, and 61%, respectively. Among those with severe lesions, only 79% were seen after the 18th birthday. However, the majority of subjects visited primary care physicians in all age groups, and 93% remained in contact with the healthcare system into early adulthood. Predictors of lack of cardiology follow-up in adulthood included male sex, a nonsevere lesion, and a history of follow-up outside a university hospital setting.

Conclusions—Lack of cardiology follow-up begins during childhood, even among those with severe lesions. This occurs despite patients being in contact with other healthcare providers. Improved communication with primary care physicians may reduce the proportion of patients lost to cardiac follow-up. **(*Circulation*. 2009;120:302-309.)**

Key Words: adults ■ congenital heart disease ■ continuity of care ■ pediatrics

The population of adult survivors of congenital heart disease (CHD) is growing rapidly, particularly those with severe lesions.[1] Adults with CHD use substantial healthcare resources compared with the general adult population.[2] For these reasons, effective transition of care from adolescence to adulthood is taking on increasing importance. Failure to receive continuity of care predisposes the young adult to delayed recognition of new or evolving cardiac problems, which in turn may complicate subsequent patient management.[3,4]

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Challenges to successful transfer of care from the pediatric to adult healthcare settings include lack of patient compliance, difficulty in adjusting to an autonomous adult healthcare environment from the more paternalistic setting of pediatric care, and patient moves to new cities and healthcare systems.[5] Transition of patients with CHD has been the subject of a number of reviews[6–14] but little investigation. Ongoing follow-up throughout the pediatric age range is also presumably a requisite of successful transfer to adult care; however, the proportion of children with CHD who are followed by cardiologists throughout childhood is not known.

Lesion-specific guidelines on the indications for and frequency of follow-up of adults with CHD have been published.[15–18] These guidelines, in conjunction with prevalence data in adults,[1] suggest that most adults with CHD require periodic evaluation by a cardiologist throughout adult life. However, to our knowledge, the success of maintaining cardiology follow-up within the pediatric age range and into adulthood has not been studied. The objectives of this study were therefore (1) to determine, at the population level, the proportion of children with CHD who fail to receive follow-up cardiac care through childhood and into early adulthood and (2) to identify risk factors for failure of follow-up.

Methods

Setting and Data Sources

The province of Quebec, Canada, provides universal access to government-funded health care. A unique healthcare number is

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Table 1. CHD Diagnoses and Corresponding *ICD-9* Codes

Group	Diagnosis	*ICD-9* Code	n (%)
Severe	Truncus arteriosus	745.0	6 (0.9)
	Transposition of the great arteries	745.1	12 (1.9)
	Tetralogy of Fallot	745.2	27 (4.2)
	Univentricular heart	745.3	4 (0.6)
	Endocardial cushion defect	745.6	34 (5.3)
	Hypoplastic left heart syndrome	746.7	1 (0.2)
Simple shunts	Ventricular septal defect	745.4	248 (38.6)
	Atrial septal defect	745.5	99 (15.4)
	Unspecified defects of septal closure	745.9	25 (3.9)
	Patent ductus arteriosus	747.0	19 (3.0)
Other lesions	Anomalies of the pulmonary valve	746.0	20 (3.1)
	Congenital tricuspid valve disease	746.1	1 (0.2)
	Ebstein's anomaly	746.2	3 (0.5)
	Congenital aortic stenosis	746.3	26 (4.0)
	Congenital aortic insufficiency	746.4	9 (1.4)
	Congenital mitral stenosis	746.5	0
	Congenital mitral insufficiency	746.6	1 (0.2)
	Coarctation of the aorta	747.1	18 (3.0)
	Other unspecified anomalies of the aorta	747.2	0
	Anomalies of the pulmonary artery	747.3	3 (0.5)
	Anomalies of the great veins	747.4	1 (0.2)
	Other unspecified anomalies of the heart	746.8, 746.9	20 (3.1)
	Other unspecified anomalies of the circulation	747.9	67 (10.4)

assigned at birth and is systematically linked to all health-related services. Province-wide databases record every inpatient and outpatient contact with the healthcare system. To be paid, physicians must submit billing data to the government, ensuring a high level of data completion. The database of the Régie de l'Assurance Maladie du Québec records physician and drug claims, and the hospital discharge database (Med-Echo) records information related to inpatient care. Together, these databases contain demographic information in addition to records of all diagnostic and therapeutic procedures performed in the province. Data were obtained from the Régie de l'Assurance Maladie du Québec and Med-Echo after permission was granted by the Commission d'Accès à l'Information du Québec and the Research Ethics Board of the McGill University Health Center Research Institute. To ensure confidentiality, patient names were omitted, and healthcare numbers were encrypted.

Study Population

All data from 1983 to 2005 in the Régie de l'Assurance Maladie du Québec and Med-Echo databases for individuals with 1 or more diagnostic codes of a CHD lesion, conforming to the *International Classification of Diseases, Ninth Revision* (*ICD-9*), were fused with the use of encrypted healthcare numbers at the McGill University Health Center. In cases in which >1 *ICD-9* diagnosis of a CHD lesion existed for a given subject, a single (most severe) diagnosis was chosen with the use of an algorithm described previously.[1] This algorithm also incorporated cardiac surgical billing codes, where applicable, to determine the most accurate diagnosis for a given individual. To validate this diagnostic algorithm, random samples were taken among 17 474 subjects with complex billing patterns, and all data for these subjects were independently reviewed by 2 CHD specialists (A.S.M., A.J.M.).

In this analysis, we included only those individuals born in 1983 who were diagnosed with CHD by a cardiologist before 6 years of age. Relevant *ICD-9* codes are listed in Table 1. Patients were divided into 3 groups, "severe," "simple shunts," and "other lesions," on the basis of on anatomic diagnosis. Data were reviewed from 1983 to 2005, until subjects were 22 years of age. Patients were excluded if they died before 22 years of age (n=39) because they were not at risk for loss of follow-up throughout the full study period.

Measurements

For the purposes of this study, cardiology follow-up was defined as an outpatient assessment by a cardiologist. The existence of an outpatient evaluation was determined with the use of billing data from the physician's claims database. Age at loss to follow-up was defined as the age at the time of the last outpatient cardiology encounter. For each age, attrition was defined as the proportion of patients who had their last cardiology follow-up at that age. The following variables, measured before age 6 years, were considered potential determinants of attrition after age 6 years: sex, CHD severity, performance of ≥ 1 invasive procedures (cardiac catheterization or cardiac surgery), ≥ 1 hospitalization for a cardiac reason, number of outpatient visits to a cardiologist, number of outpatient visits to physicians other than cardiologists, type of residence (urban, rural, or mixed) as determined by postal code,[19] location of last cardiology visit before age 6 years (university hospital versus satellite clinic in a community hospital or nonhospital setting), and change in address within 3 years of the last cardiologist visit (as determined by a change in the first 3 digits of the postal code). The number of noncardiology physician visits was categorized as low (lowest quartile), medium (between 25th and 75th percentiles), or high (highest quartile).

Statistical Analysis

Descriptive statistics included proportions for categorical variables and medians and interquartile ranges for continuous variables. Both cardiology follow-up and attrition in the study population were initially analyzed for 3 age groups that represent different eras of childhood development: preadolescence (6 to 12 years), adolescence (13 to 17 years), and young adulthood (18 to 22 years). However, for the main analyses, we generated Kaplan-Meier plots to describe age at loss to follow-up and treated age as a continuous variable with 1-year increments. Time zero was set at birth, and events were defined as the last visit in childhood that was not followed by a visit in adulthood (age 18 to 22 years). Thus, all individuals having cardiology follow-up from age 18 to 22 years were censored at 18 years. Two separate multivariable logistic regression models were used to identify the predictors of (1) loss to follow-up before age 6 years and (2) loss to follow-up before age 18 years. For all continuous variables, we checked the assumption of a linear trend across the quartiles by plotting the median value for each quartile against the corresponding logit of the probability of having cardiology follow-up. The continuous variables that were consistent with the linearity assumption were entered in the model as linear, and their corresponding odds ratios are presented per 1-U increase in the continuous predictor. For variables that violated the linearity assumption, we used dummy indicators to compare each higher quartile with the lowest one. However, if estimates from 2 adjacent categories were similar, we pooled together the respective adjacent categories. The initial models included all candidate predictors listed above. The final models were selected through a backward variable elimination procedure. Variables were kept in the models if statistically significant at $P \leq 0.05$ for a 2-tailed Wald test. From the final multivariable models, we report adjusted odds ratios (ORs) and 95% confidence intervals (CIs). All analyses were performed with the use of SAS statistical software (version 8.02; Cary, NC).

The authors had full access to and take full responsibility for the integrity of the data. All authors have read and agree to the manuscript as written.

Results

One thousand forty-five children were born with CHD in Quebec in 1983 (among 87 739 live births in the province),[20] of which 682 (65%) were diagnosed before 6 years of age. Of these, 643 (94%) were alive at age 22 years and form the study population for analysis. Males accounted for 335 subjects (52%). Severe lesions were present in 84 (13%), simple shunts in 390 (61%), and other defects in 169 (26%) (Table 1). Baseline characteristics (at age 6 years) are summarized in Table 2.

Failure to receive outpatient cardiology follow-up after the 6th and 13th birthday occurred in 177 children (28%) and 300 children (47%), respectively (Figure 1). Between 18 and 22 years, only 39% of subjects were still being seen in an outpatient cardiology setting. However, 87% of 18- to 22-year-old subjects were evaluated by a primary care physician, and 93% had 1 or more contacts with the healthcare system (Figure 2). After subjects who may have been discharged from cardiac care (all simple shunts, abnormalities of the pulmonary artery, and abnormalities of the pulmonary valve; n=413) were excluded, failure to receive outpatient cardiology follow-up after the 6th, 13th, and 18th birthday occurred in 55 (24%), 84 (37%), and 107 patients (47%), respectively. Even among subjects with severe lesions, 21% did not have an outpatient evaluation by a cardiologist between the ages of 18 and 22 years. Follow-up of the most prevalent lesions, by diagnosis, is summarized in Figure 3.

Table 2. Baseline Characteristics, as Measured Before Sixth Birthday

Potential Determinants of Attrition	All (n=643)	Outpatient Visit to Cardiologist Age 18–22 y: Yes (n=249) (%)	Outpatient Visit to Cardiologist Age 18–22 y: No (n=394) (%)
Male sex	335	113 (45)	222 (56)
CHD lesion			
Severe defects	84	66 (27)	18 (5)
Simple shunts	390	115 (46)	275 (70)
Other defects	169	68 (27)	101 (26)
Invasive cardiac procedure (surgery or catheterization) <age 6 y	196	124 (50)	72 (18)
Cardiac hospitalization <age 6 y	408	186 (75)	222 (56)
Median No. of outpatient visits to a cardiologist <age 6 y (IQR)	3 (6–60)	5 (9–60)	2 (4–38)
Median No. of outpatient visits to a physician (noncardiology) <age 6 y (IQR)	91 (63–127)	111 (83–150)	81 (56–111)
Last cardiology visit (before age 6 y) in university hospital setting	496	202 (81)	294 (75)
Residence			
Urban	290	116 (47)	174 (44)
Mixed	265	100 (40)	165 (42)
Rural	71	33 (13)	38 (10)
Missing	17	0 (0)	17 (4)
Change in address within 3 y of last cardiology visit			
Yes	118	54 (22)	64 (16)
Missing	21	2 (1)	19 (5)

IQR indicates interquartile range.

In multivariable analysis, the following variables were independently associated with a higher risk of loss of follow-up during childhood (ie, last seen before age 18 years) (Table 3): male sex (OR, 1.52; 95% CI, 1.05 to 2.20), having a simple shunt lesion compared with a severe lesion (OR, 4.14; 95% CI, 2.17 to 7.87), no cardiac-related hospitalization before age 6 years (versus cardiac hospitalization with invasive procedure; OR, 1.93; 95% CI, 1.18 to 3.17), cardiac hospitalization before age 6 years but without an invasive procedure (versus cardiac hospitalization with invasive procedure; OR, 2.22; 95% CI, 1.36 to 3.62), fewer visits to a cardiologist (OR, 1.15 per 1 fewer visit; 95% CI, 1.09 to 1.21), fewer visits to noncardiology physicians (lowest compared with highest quartile; OR, 2.42; 95% CI, 1.39 to 4.22), and last cardiologist visit outside of a university hospital setting (OR, 1.63; 95% CI, 1.02 to 2.61).

The following variables were independently associated with lack of follow-up early in childhood (ie, never seen after

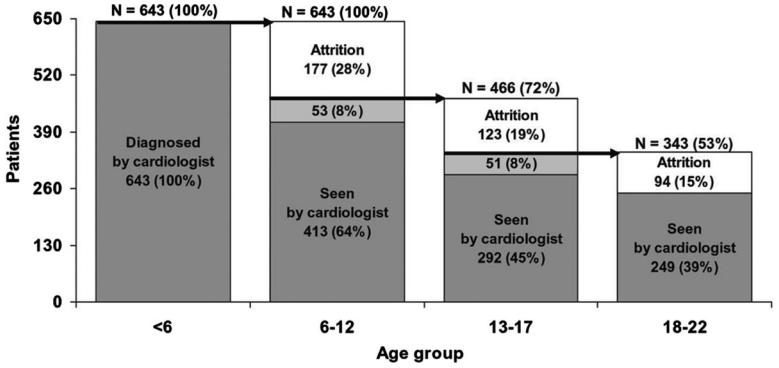

Figure 1. Loss of follow-up from age 6 to 22 years among the entire study cohort. The light gray bars indicate patients who were not seen by a cardiologist within the indicated age range but were seen again by a cardiologist in an older age group (ie, transiently lost to follow-up).

age 6 years): no cardiac-related hospitalization before age 6 years (versus cardiac hospitalization with invasive procedure; OR, 1.88; 95% CI, 1.02 to 3.47), cardiac hospitalization before age 6 years but without an invasive procedure (versus cardiac hospitalization with invasive procedure; OR, 1.90; 95% CI, 1.02 to 3.53), fewer visits to a cardiologist (OR, 1.45 per 1 visit decrease; 95% CI, 1.30 to 1.62), and fewer visits to noncardiology physicians (lowest compared with highest quartile users; OR, 2.74; 95% CI, 1.53 to 4.90).

Discussion

In a publicly funded healthcare system with universal access to medical care, we found that a substantial proportion of children diagnosed with CHD before 6 years of age did not receive outpatient cardiology follow-up either later in childhood or in early adulthood. Among all subjects with CHD, the largest attrition from cardiology follow-up occurred during childhood rather than after the transition to adult care, if it is assumed that transition occurred at age 18 years. Even among subjects with severe lesions, lack of follow-up was an important problem. More than 1 in 5 young adults with severe CHD were not seen by a cardiologist during a 5-year period (age 18 to 22 years inclusive). This occurred despite having other contacts with the healthcare system, evidence that these subjects were still living in the province of Quebec and had access to health care. The strengths of this study include the long duration of follow-up, the ability to identify any contact within a universal-access healthcare system covering a large geographic area, and the confirmation that the great majority of subjects were still living in Quebec.

To our knowledge, there are few guidelines on the indications for or frequency of follow-up of children with CHD. Wernovsky et al[21] employed a series of "consensus meetings" among members of a single institution to derive guidelines on the follow-up of children with transposition of the great arteries, tetralogy of Fallot, and various forms of single ventricle. These authors recommended follow-up through adolescence and transition to adult CHD care for all of these lesions. Published guidelines on adults with CHD recommend periodic follow-up, by cardiologists, of patients with most CHD lesions,[15–17] implying the need for follow-up during childhood and adolescence in order to be transitioned effectively to adult care. The frequency of loss to follow-up during the pediatric age range has not been studied previously, although the low rate of transition to adult care has been recognized previously.[22] Our findings are in agreement with those of Reid et al,[22] who studied 19- to 21-year-old subjects with CHD previously managed at a large Canadian pediatric tertiary care center to determine the proportion who had transferred to adult care. Only 47% of that cohort had been seen at an adult congenital cardiac clinic, comparable to our findings, particularly given that a minority of their cohort had simple shunts. However, there are important differences between our study and that of Reid and colleagues. We demonstrated that the attrition from cardiac care begins in early childhood, well before the transition to adult care facilities. Second, we did not distinguish between follow-up with a general cardiologist versus an adult CHD subspecialist. Third, our data sources (administrative databases) allowed us

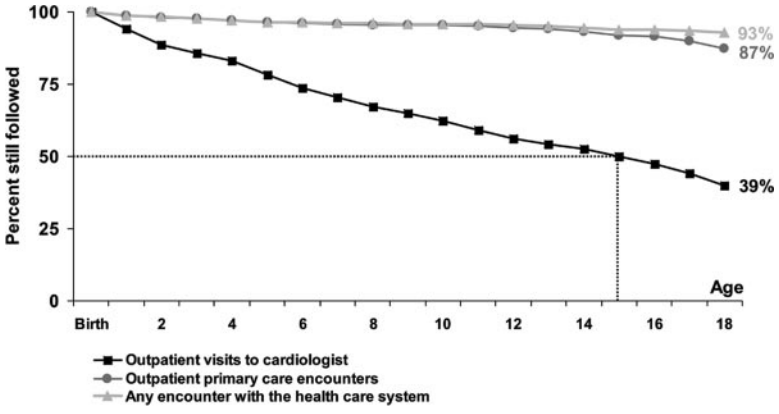

Figure 2. The proportion of patients in contact with the healthcare system. The gap between "outpatient primary care encounters" and "outpatient visits to cardiologist" widened with increasing age. The median age at loss to follow-up from cardiology care was 15 years.

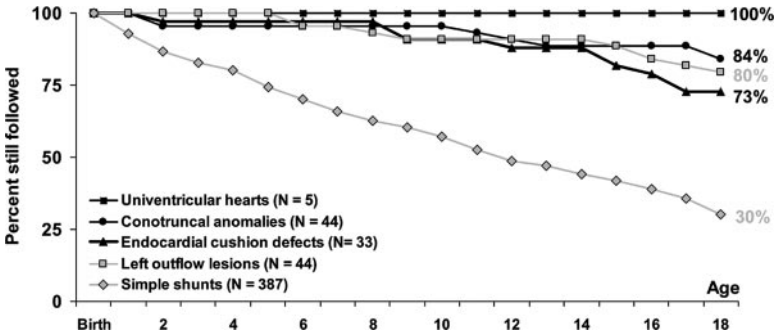

Figure 3. Outpatient cardiology follow-up stratified by severity of CHD. "Univentricular hearts" includes hypoplastic left heart syndrome. "Conotruncal anomalies" refers to tetralogy of Fallot, truncus arteriosus, and transposition of the great arteries. "Left outflow lesions" refers to congenital aortic stenosis and coarctation of the aorta. Among children with simple shunts, the median age at loss to follow-up from cardiology care was 12 years. Note that minor discrepancies exist between the sample size in this figure and the sample size in Table 1. This occurred because 5 subjects were excluded from Figure 3 because they did not have any outpatient visit to a cardiologist before age 18 years (their first CHD diagnosis by a cardiologist before age 6 years was made in the hospital or outside of Quebec).

to systematically capture both visits with cardiologists and other healthcare professionals without having to rely on patient-reported medical care or adult CHD clinic–reported care.

Simple shunts and mild valvar pulmonary stenosis may not require cardiology follow-up in some cases,[15] and therefore some of our patients may have been discharged from cardiac care rather than lost to follow-up. Our databases did not allow us to discriminate those patients with simple shunts who still required cardiology follow-up (eg, because of pulmonary hypertension or arrhythmia) versus those who did not. For this reason, simple shunts and valvar pulmonary stenosis were excluded in our sensitivity analysis. However, even after these lesions were excluded, failure to obtain cardiology follow-up occurred in almost half of the study population.

Males were more likely to be lost to follow-up before adulthood than females. This is consistent with the increased prevalence of risk-taking behaviors in males, though other studies of missed general medical appointments in adolescents have not found significant differences between males and females.[23,24] Greater attention to male adolescents with risk-taking behavior may be required by CHD transition programs. Subjects with a history of hospitalization, previous invasive procedures, and more frequent physician visits in early childhood were all more likely to transition to adult cardiac care, independent of the severity of their CHD lesion. These findings are consistent with a previous report, in which more cardiovascular surgeries in childhood correlated with successful transfer to adult care.[22] Having cardiology visits outside a university hospital setting was associated with a greater risk of loss to follow-up. The reasons for this are unknown, although this may relate to the availability of comprehensive transition programs outside of academic centers. This finding requires confirmation in other studies before recommendations can be made on appropriate venues to deliver outpatient pediatric cardiac care.

Compared with school-age children, adolescents and young adults were more likely to be seen by primary care physicians than by cardiologists (Figure 2). These findings suggest that primary care physicians are either unaware that their patients are not being seen concurrently by a cardiologist or are unaware of the ongoing need for cardiology follow-up. Improved communication between cardiologists and primary care providers, emphasizing the potential for late cardiac complications and the need for long-term cardiac care, may help to reduce the proportion of patients who are lost to cardiology follow-up.

We sought to assess the rate of follow-up, not to make recommendations about which lesions require follow-up or by whom patients should be seen. Current guidelines state that patients with complex or moderate disease, which largely corresponds to our definition of severe and other lesions, should have periodic follow-up in adult CHD centers.[25] We believe that failure to be seen at least once between 18 and 22 years of age indicates that these recommendations are not being met.

The proportion of patients lost to cardiology follow-up in this study, conducted in a jurisdiction with universal access to healthcare, probably represents a "best-case" scenario. Given the challenges of employability and insurability inherent to adults with CHD,[26] it is likely that compliance with cardiology follow-up is no better in countries that do not provide universal access to health care and may be worse. The high cost of physician's services[27] may serve as a barrier to access to care for patients without health insurance.

Only 65% of children born in Quebec in 1983 with CHD were diagnosed before 6 years of age. We are not aware of other population-based studies describing the proportion of children with CHD diagnosed in early childhood compared with diagnoses in later childhood or adolescence. Studies describing the childhood prevalence of CHD from large referral centers are biased toward detecting more severe lesions at younger ages and do not account for all subjects with disorders such as atrial septal defects, milder forms of Ebstein anomaly, coarctation of the aorta, or bicuspid aortic valve with mild aortic stenosis, regurgitation, or both that remain undiagnosed. Furthermore, access to pediatric cardiologists in Quebec from 1983 to 1989 was less than it is in the current era, especially for children living in rural areas, which would also have resulted in delayed diagnosis of some children. The Quebec telemedi-

Table 3. Multivariable Analysis

Predictors Before Age 6 y	OR (95% CI) Loss to Follow-Up Before Age 6 y	OR (95% CI) Loss to Follow-Up Before Age 18 y
Sex		
Females	...	1.00
Males	...	1.52 (1.05–2.20)
CHD severity		
Severe CHD	...	1.00
Simple shunts	...	4.14 (2.17–7.87)
Other CHD	...	2.49 (1.25–4.98)
Hospitalization before age 6 y		
Hospitalization with invasive procedure	1.00	1.00
No hospitalization	1.88 (1.02–3.47)	1.93 (1.18–3.17)
Hospitalization without invasive procedure	1.90 (1.02–3.53)	2.22 (1.36–3.62)
No. of outpatient visits to cardiologist before age 6 y (per 1 visit increase)	0.69 (0.62–0.77)	0.87 (0.83–0.92)
No. of outpatient visits to other physicians before age 6 y		
Highest quartile (>6 visits)	1.00	1.00
Interquartile (2 to 6 visits)	1.46 (0.88–2.42)	1.43 (0.93–2.22)
Lowest quartile (<2 visits)	2.74 (1.53–4.90)	2.42 (1.39–4.22)
Location of the last visit to cardiologist before age 6 y		
University hospital setting	...	1.00
Outside a university hospital setting	...	1.63 (1.02–2.61)

Ellipses reflect variables that were not significant and were therefore dropped from the final model. Neither type of residence (urban vs rural) nor a change in address in the 3 y after the last visit to a cardiologist before age 6 y was a significant predictor in either model.

cine program, providing outreach to rural areas, began in 2000.[28] The number of pediatric cardiologists in the province has more than doubled since the mid 1980s, whereas the birth rate has decreased from 13.3/1000 in 1983 to 10.9/1000 in 2007, with a lowest rate of 9.8/1000 in 2002.[20] Finally, some patients lived outside Quebec and moved to the province at ≥6 years of age. Under these circumstances, the first record of such individuals in our databases occurred at the time of the first visit to a Quebec cardiologist. All subjects were born in 1983; however, birthplace in Quebec was not an inclusion criterion.

Ninety-four percent of all children born with CHD in 1983 survived to age 22 years. Nieminen et al[29] reported a 6.8% mortality rate among all congenital heart procedures performed in Finland between 1980 and 1989, the same time period as our study. Among those who underwent surgery in Finland between 1953 and 1989, 92% were still alive by age 22 years.[30] Thus, given that 196 (29%) of 682 children in our study underwent an invasive cardiac procedure before age 6 years, we would anticipate only ≈16 deaths by age 22 years. In fact, there were 39 deaths in our Quebec cohort, higher than would be expected, but this difference is unlikely to have resulted in a disproportionately large number of survivors with low-complexity lesions. Indeed, 13% of our study population had a severe lesion. This is consistent with the estimate that 15% of adults in the United States have complex forms of CHD, reported by the 32nd Bethesda conference.[25] Therefore, we believe that our study population is representative of what would be found in other jurisdictions.

Our data did not allow us to examine whether loss to follow-up is associated with higher risk of death or other clinical outcomes. Deaths among adults with CHD become increasingly prevalent in adults aged >25 years,[31] but our follow-up stops at age 22 years. We could not link loss to follow-up to childhood deaths also because of the limited number of events; only 21 deaths occurred from age 6 to 22 years. Similarly, hospitalizations become increasingly common in adults aged >22 years.[31] Therefore, further studies with longer follow-up are required to appropriately link loss to follow-up with outcomes.

Our study has limited clinical information, an issue inherent to administrative databases. Therefore, we were unable to examine other potential risk factors for loss of follow-up, such as risk-taking behaviors[22,32] (eg, smoking), compliance with subacute bacterial endocarditis prophylaxis,[22] greater independence in attending outpatient appointments,[22,33,34] socioeconomic status, family functioning, and health beliefs.[22] Although some degree of misclassification is inevitable with administrative databases, manual review of all available data on >2000 patients (randomly chosen among 17 474 subjects with complex billing patterns) allows us to be confident that diagnosis misclassification occurred in no more than a trivial proportion of all subjects in these databases. Indeed, the use of administrative databases is also an important strength because these databases allowed us to capture a large number of patients, to follow them until age 22 years, and to identify all outpatient cardiology and primary care encounters, whether in tertiary care hospitals, community hospitals, or physician's offices. Determining that a young adult was seen by a cardiologist in an outpatient setting does not imply that the transfer of care met the definition of transition, as suggested by Blum and colleagues,[35] namely, "the purposeful, planned movement of adolescents and young adults . . . from child-centered to adult health-care systems." Therefore, our findings may overestimate the true rate of successful follow-up within the pediatric age range and the rate of successful transition to adult care. We included only subjects who were still alive at age 22 years. It is possible that the few patients who died before age 22 years (n=39) and who presumably had the most severe CHD lesions were more likely to obtain regular cardiology follow-up before death. For young adults, we did not distinguish between follow-up by a general cardiologist versus an adult congenital heart

specialist, a distinction that may be relevant for some lesions.[25]

In summary, this study demonstrates that loss to follow-up is a prevalent problem within the pediatric age range. This supports anecdotal observations that despite scheduled follow-up visits, some patients, including those with severe CHD lesions, fail to attend cardiology clinics. Developmentally appropriate discussions should begin in childhood and be repeated with and without parents in adolescence, emphasizing the need for lifelong cardiac care. Education of patients, parents, and primary care providers may contribute to reducing the proportion of CHD patients lost to follow-up. Particular attention should be paid to patients identified in our analyses to be at highest risk of loss to follow-up, such as males and those followed outside a university hospital setting. Comprehensive transition programs should exist for transfer from pediatric to adult care facilities. Future studies are needed to examine the impact of transition programs and to better understand the factors associated with dropout within the pediatric age range. Planning effective transition of care should begin in childhood.

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Disclosures

None.

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CLINICAL PERSPECTIVE

Many patients with congenital heart disease require lifelong care. However, the proportions of patients who are lost to follow-up during childhood and early adulthood are not well described, nor are the risk factors for loss to follow-up. We used administrative databases in the province of Quebec, Canada, to describe outpatient cardiology follow-up among all persons born in 1983 and diagnosed with congenital heart disease before their sixth birthday. Subjects were followed until 22 years of age. Loss to follow-up was an important problem both within the pediatric age range and at the time of transition to adult care. Only 39% of the cohort saw a cardiologist between 18 and 22 years of age. Among those with severe lesions, only 79% were seen by a cardiologist in early adulthood. Reasons for loss to follow-up included male sex, having a nonsevere congenital heart disease lesion, and having previous cardiology care outside of a university hospital setting. The great majority of patients were still seeing primary care physicians, however, implying that there may be a lack of awareness about the need for follow-up cardiac care within the medical community. These findings have important implications for both pediatric and adult congenital cardiologists. Concerted efforts are required to contact children and families who do not attend clinic visits. Improved communication from cardiologists to primary care physicians about the potential for late cardiac complications and the need for long-term follow-up may help. Adolescents and their families require sufficient preparation for the transition to adult congenital heart disease healthcare settings.