

# Prevalence and Correlates of Successful Transfer From Pediatric to Adult Health Care Among a Cohort of Young Adults With Complex Congenital Heart Defects

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**ABSTRACT.** *Objectives.* More than 85% of children born today with chronic medical conditions will live to adulthood, and many should transfer from pediatric to adult health care. The numbers of adults with congenital heart defects (CHDs) are increasing rapidly. Current guidelines recommend that just over half of adult CHD patients should be seen every 12 to 24 months by a cardiologist with specific CHD expertise at a regional CHD center, because they are at risk for serious complications (eg, reoperation and/or arrhythmias) and premature mortality. The present study aimed to determine the percent of young adults with CHDs who successfully transferred from pediatric to adult care and examine correlates of successful transfer.

*Design.* Cross-sectional study with prevalence data from an entire cohort.

*Setting and Patients.* All patients ( $n = 360$ ) aged 19 to 21 years with complex CHDs who, according to current practice guidelines, should be seen annually at a specialized adult CHD center were identified from the database of the cardiology program at the Hospital for Sick Children in Toronto, Canada, a pediatric tertiary care center. Of these patients, 234 completed measures about health beliefs, health behaviors, and medical care since age 18 years.

*Main Outcome Measure.* All 15 specialized adult CHD centers in Canada formed the Canadian Adult Congenital Heart (CACH) Network. Attendance for at least 1 follow-up appointment at a CACH center before the age of 22 years was ascertained for all eligible patients. Attendance at a CACH center provides a clear criterion for successful transfer.

*Results.* In the total cohort, 47% (95% confidence interval [CI]: 42–52) had transferred successfully to adult care. There was no difference in rates of successful trans-

fer between patients consenting to complete questionnaires (48%) and those who declined (47%). More than one quarter (27%) of the patients reported having had no cardiac appointments since 18 years.

In multivariate analyses of the entire cohort, successful transfer was significantly associated with more pediatric cardiovascular surgeries (odds ratio [OR]: 2.47; 95% CI: 1.40–4.37), older age at last visit to the Hospital for Sick Children (OR: 1.29; 95% CI: 1.10–1.51), and documented recommendations in the medical chart for follow-up at a CACH center. In multivariate analyses of the patients completing questionnaires, successful transfer was significantly related to documented recommendations and patient beliefs that adult CHD care should be at a CACH center (OR: 3.64; 95% CI: 1.34–9.90). Comorbid conditions (OR: 3.13; 95% CI: 1.13–8.67), not using substances (eg, binge drinking; OR: 0.18; 95% CI: 0.07–0.50), using dental antibiotic prophylaxis (OR: 4.23; 95% CI: 1.48–12.06), and attending cardiac appointments without parents or siblings (OR: 6.59; 95% CI: 1.61–27.00) also correlated with successful transfer.

*Conclusions.* This is the first study to document the percent of young adults with a chronic illness who successfully transfer to adult care in a timely manner. Patients were from an entire birth cohort from the largest pediatric cardiac center in Canada, and outcome data were obtained on all eligible patients. Similar data should be obtained for other chronic illnesses. There is need for considerable improvement in the numbers of young adults with CHDs who successfully transfer to adult care. At-risk adolescents with CHDs should begin the transition process before their teens, should be educated in the importance of antibiotic prophylaxis, should be contacted if a follow-up appointment is missed, and should be directed to a specific CHD cardiologist or program, with the planned timing being stated explicitly.

Adult care needs to be discussed in the pediatric setting, and patients must acquire appropriate beliefs about adult care well before transfer. Developmentally appropriate, staged discussions involving the patient, with and without parents, throughout adolescence may help patients acquire these beliefs and an understanding of the need for ongoing care. Improved continuity of pediatric care and provision of clear details for adult follow-up might be sufficient to cause substantive improvements in successful transfer. An understanding of why patients drop out of pediatric care may be needed to improve the continuity of care throughout adolescence.

Almost one quarter of the patients believed adult care should be somewhere other than at a CACH center despite opposite recommendations. For these patients, a single discussion of adult care during the final pediatric visit may be too little, too late. In addition to earlier discussions, multiple mechanisms such as referral letters

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and transition clinics are needed. Similarly, patients engaging in multiple risky or poor health behaviors such as substance use may need more intensive programs to make substantial changes in these behaviors, which hopefully would lead to successful transfer.

Overall, these data support the view that transition to adult care (a planned process of discussing and preparing for transfer to an adult health center) is important and should begin well before patients are transferred. The future health of adults with chronic conditions may depend on our ability to make these changes. *Pediatrics* 2004;113:e197–e205. URL: <http://www.pediatrics.org/cgi/content/full/113/3/e197>; congenital heart defects, transition, transfer, continuity of care, adolescent, young adult.

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ABBREVIATIONS. CHD, congenital heart defect; CACH, Canadian Adult Congenital Heart; HSC, Hospital for Sick Children; TCCCA, Toronto Congenital Cardiac Center for Adults; CI, confidence interval; OR, odds ratio.

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More than 85% of children born today with chronic medical conditions will live to adulthood.<sup>1</sup> Annually, ~500 000 adolescents with chronic medical conditions in the United States and ~50 000 in Canada should transfer from pediatric to adult care.<sup>2,3</sup> Transition has been defined as the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems” (p 570)<sup>4</sup>; it addresses both physical and psychosocial factors.<sup>1</sup> The need for proper transition or transfer (ie, a change in the location where care is provided<sup>5</sup>) is recommended for many chronic conditions (eg, diabetes, cystic fibrosis, and arthritis<sup>6</sup>) and highlighted in a recent consensus statement.<sup>2</sup> Transition is discussed frequently (eg, refs 7–12) but studied rarely (eg, refs 1 and 13–17). In Canada, government funding of health care typically requires individuals >18 years old to be seen in an adult hospital, although variation by center and provinces may result in transfer after 16 years old. In the United States, the age of transfer to adult care varies due to the diversity of health care coverage. An age of 18 years or the end of high school has been recommended as a typical age for transfer to adult care.<sup>8,18</sup>

The importance of transition was raised in all 5 task-force reports from the recent Bethesda Conference on the Care of the Adult With Congenital Heart Disease.<sup>18–22</sup> There are close to 100 000 adults with congenital heart defects (CHDs) living in Canada and 1 million in the United States.<sup>19,23</sup> Current guidelines recommend that just over half of adult CHD patients should be seen every 12 to 24 months by a cardiologist with specific CHD expertise at a regional CHD center,<sup>19,21,24–26</sup> because these individuals are at risk for serious complications (eg, reoperation,<sup>27,28</sup> arrhythmias<sup>29,30</sup>, and premature mortality<sup>29</sup>). Although discussed in numerous publications (eg, refs 31–33), only Kools et al,<sup>34</sup> who interviewed 8 patients regarding experiences in adult hospitals, obtained data from patients with CHDs.

The first objective of the present study was to determine the prevalence of successful transfer from

pediatric to adult care among young adults with CHDs. In Canada, all 15 specialized adult CHD centers formed the Canadian Adult Congenital Heart (CACH) Network; attendance at a CACH center provides a clear criterion for successful transfer. We also describe the type of medical care patients reported receiving in the recent past. The second objective was to examine correlates of successful transfer to adult care. The empirical and theoretical literature on clinic attendance and health behaviors (eg, ref 35) was used to select potential correlates. We hypothesized that successful transfer would be associated with 1) health care system factors (eg, closer distance to the nearest CACH center,<sup>36</sup> more-frequent and more-recent adolescent cardiac appointments,<sup>31,37</sup> and recommendations by the pediatric cardiologist<sup>5,11</sup>); 2) family factors (eg, higher socioeconomic status and better family functioning<sup>38</sup>); and 3) individual factors (eg, more pediatric cardiovascular surgeries, poorer health status,<sup>39</sup> better psychological adjustment,<sup>40</sup> fewer health-risk behaviors,<sup>41</sup> greater independence in attending cardiac appointments,<sup>42,43</sup> higher risk expectancies and greater self-efficacy,<sup>44–47</sup> belief that adult CHD care should take place at a CACH center annually, and lower preferences for self-care<sup>48</sup>).

## METHODS

### Cohort Description and Data Collection

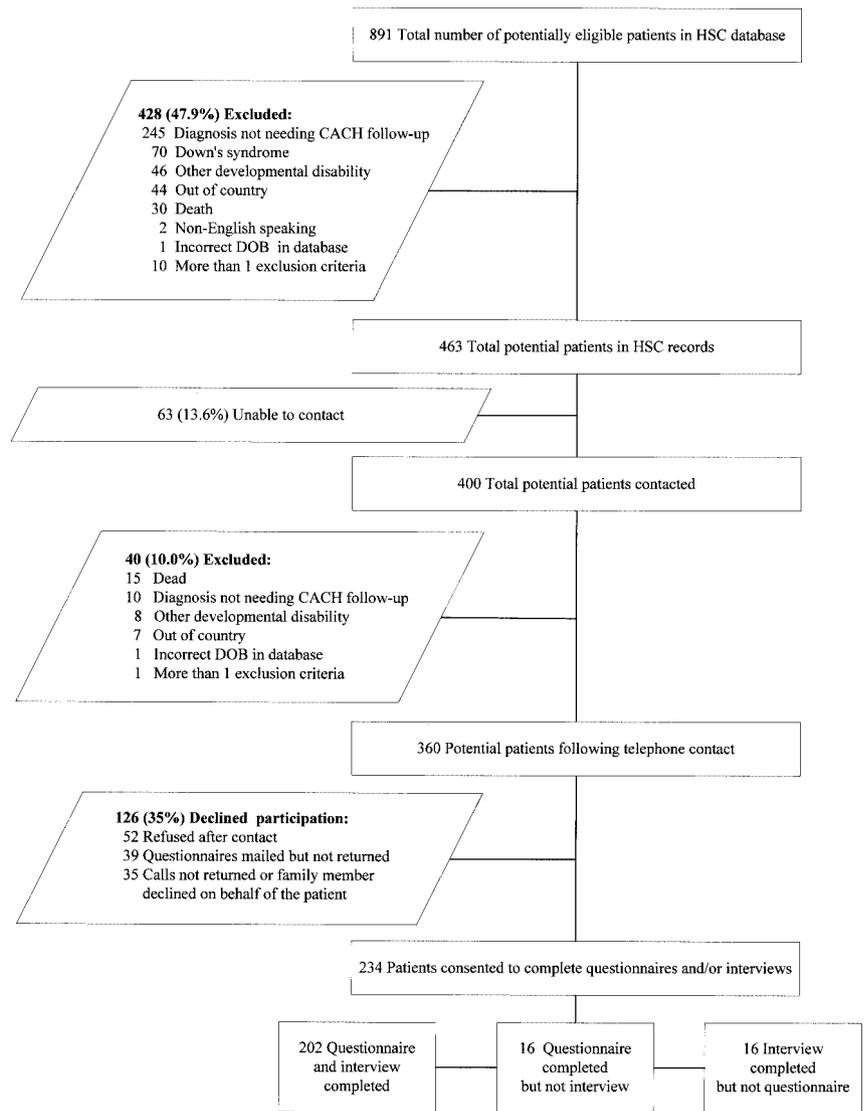
Patients were selected from the database of the Hospital for Sick Children (HSC) in Toronto, the largest pediatric cardiac center in Canada. The HSC is a tertiary care facility providing specialized cardiology care. Primary care for complex patients is provided by the patients’ responsible pediatrician (rarely a pediatric cardiologist) or family physician in the community, with close communication and coordination with the cardiologist. Transfer to adult care is usually arranged by the patient’s cardiologist before the patient reaches 18 years of age, although during the period of the study no formal “transition program” was in place other than the transfer of medical records. From the entire population of patients seen at the clinic and born between June 1, 1978 and May 31, 1980, we identified patients with complex heart defects that, according to consensus criteria<sup>49</sup> and standards at the Toronto Congenital Cardiac Center for Adults (TCCCA), are recommended for annual follow-up at a specialized adult CHD clinic. A cardiologist specializing in CHDs (G.D.W.) reviewed the diagnostic codes used in the HSC database for those that matched the consensus criteria. A computer algorithm identified a total of 891 potential patients whose charts were then reviewed. Figure 1 shows the exclusion criteria and how the final cohort was obtained.

Eligible patients were mailed a consent form, questionnaires, and a stamped, addressed return envelope. Approximately 2 weeks later, patients were telephoned to address any difficulties with the questionnaires and to schedule an interview. Interviews were audiotaped and transcribed. Outcome data were obtained for all 360 eligible patients as of March 1, 2000. Patients had between 1 and 30 cardiac diagnoses (mean: 8.3; standard deviation: 5.31); diagnoses for each patient were reviewed (by G.D.W.), and a primary diagnosis was determined. There were 162 men (45.0%) who were eligible. Patients were 19 ( $n = 58$ ; 16.1%), 20 ( $n = 174$ ; 48.3%), or 21 ( $n = 128$ ; 35.6%) years old as of March 2000. Table 1 presents additional demographic characteristics. The Research Ethics Boards at HSC and University Health Network approved this study.

### Outcome Variables

Successful transfer to adult care was the primary outcome variable, operationally defined as the patient having attended at least 1 appointment of any type (eg, clinic, echocardiogram, cardiac catheterization, or surgical) at a CACH center. Appointments for eligible patients were obtained from the TCCCA database.

**Fig 1.** Patient exclusion criteria, recruitment, and enrollment. Patients who did not meet the diagnostic inclusion criteria, were developmentally disabled, non-English speaking, or lived outside of Canada were excluded either at chart review or after initial contact with patients. Patients without valid addresses also were excluded. Multiple sources were searched in trying to obtain valid address: HSC medical chart, HSC cardiac clinic chart, HSC cardiologist records, Internet, family doctor or pediatrician, family member, or CACH centers. DOB indicates date of birth.



Appointments for patients who had not had an appointment at the TCCCA were obtained from the 14 other CACH centers.

The second outcome was patient-reported medical visits since 18 years old to 1) family doctor or walk-in clinic doctor, 2) general cardiologist, or 3) cardiologist who specialized in CHDs at an adult congenital heart center. Patients who reported seeing a CHD cardiologist at a children's hospital were coded as having seen a pediatric cardiologist. Self-reports were combined with CACH center data in terms of specialization of care (ie, no care, family doctor, general cardiologist, pediatric cardiologist, or CACH cardiologist).

### Predictor Variables

Patients provided demographic information: by using postal codes the linear distance to the nearest CACH center<sup>50</sup> was computed, and the average family income for the patient's enumeration area was used for socioeconomic status.<sup>51</sup> From the HSC cardiac records, the number of cardiac surgeries, pediatric health care since 10 years old, and recommendations for where and when adult care should take place were abstracted. Patients were asked: "In your opinion, which is the most appropriate type of doctor for the care of your congenital heart defect: (a) family doctor, (b) general cardiologists, (c) cardiologist at an adult congenital heart center, or (d) other?" Patients also rated their expected frequency of adult cardiac follow-up.

Patients rated their family functioning by using a standardized questionnaire.<sup>52,53</sup> Using age and gender norms, 3 variables from the SF-36 were computed: global health status, physical function-

ing, and mental health.<sup>54</sup> Patients indicated comorbid medical conditions from a standardized list<sup>55</sup> and rated activity restrictions by using 4 response options (1 [no restrictions] to 4 [complete restriction on physical activity]).

Activity levels,<sup>56</sup> substance use (eg, binge drinking, illegal drug use), risky travel behavior (eg, drinking and driving), and risky sexual behavior, typically based on the past 30 days, were measured by using standardized questionnaires<sup>57,58</sup>; composite risk scores were developed by using established criteria when available.<sup>59</sup> Dental health items included frequency of dental appointments and brushing and flossing teeth, and prophylactic antibiotic use before dental procedures that may cause bleeding, which is one of the few CHD-specific health behaviors

Based on previous studies (eg, refs 60–62), risk-perception and self-efficacy questions were developed for attending cardiac appointments, exercise, antibiotics prophylaxis, taking cardiac medications, and quitting smoking. Risk of CHD complications and self-efficacy to affect heart health and well being in general were assessed also. General preferences for self-care were assessed by using the behavioral involvement subscale of the Krantz Health Opinion Survey as it has been related to clinic attendance.<sup>48</sup>

In the interview, patients described any negative health effects due to their CHD (responses were categorized as none or at least 1 CHD-related symptom), were asked about their independence in attending cardiology appointments (eg, attending alone or with parents), and reported details on adolescent cardiac appointments. Using a coding scheme, interrater reliability calculated on

**TABLE 1.** Demographic Characteristics of the Final Sample of Eligible Patients and for Patients Who Completed Questionnaires

	<i>n</i>	%
Demographic variables for all eligible patients		
Primary diagnosis		
Left ventricular outflow tract obstruction, atrioventricular, or ventricular septal defect	90	25.0
Tetralogy of Fallot	47	13.1
Coarctation	36	10.0
Unrepaired atrial septal defect	28	7.8
Fontan	27	7.5
Mustard repairs	22	6.1
Conduits and tunnels	20	5.6
Repaired total anomalous pulmonary venous connection	13	3.6
Palliative shunts	6	1.7
Other diagnoses identical for ≤4 patients	68	18.9
Demographic variables for patients completing questionnaires		
Marital status*		
Single/never married	208	95.9
Married/common-in law/separated	9	4.1
Place of residence†		
Living with parents	150	70.1
Spouse, partner, friend, college/university residence, other family member, or family friend	52	24.3
On own	12	5.6
Education/employment status*		
Student	79	36.4
Student and working	70	32.3
Working full time	29	13.4
Working part time	18	8.3
Unemployed but looking for work	14	6.5
Unable to work due to medical reasons	4	1.8
Unemployed, homemaker, and unable to work due to medical reasons	3	1.4
Educational attainment*		
Grades 9–11	29	13.4
High school graduate	99	45.6
Trade or technical school	2	.9
Some community college	27	12.4
Community college graduate	11	5.1
Some university	49	22.6

Note: For all eligible patients, *n* = 360, and for patients who completed questionnaires, *n* = 218.

\* Data were missing for 1 patient.

† Data were missing for 4 patients.

4 patients' interviews yielding average exact agreement >97%; most questions had 100% agreement.

### Statistical Analyses

Bivariate relations between the predictor variables and successful transfer were examined. Conceptually similar categories were combined to reduce the number of cells with small sample sizes (ie, <5 patients). (Descriptions of each variable and coding are available on request.) Two sets of analyses examining correlates of successful transfer were conducted. The first used data available for all 360 eligible patients. The second used data from patients who completed questionnaires.

Variables with significant bivariate relations with successful transfer were used in logistic regressions. The 16 patients with missing data for >3 of the 18 predictor variables used in the logistic regressions were dropped from these analyses. For other patients with missing data, the mode, for categorical variables, and the mean, for continuous variables, were substituted.<sup>63</sup> Variables were entered in logistic regressions in 4 blocks based on temporal occurrence: 1) demographic and pediatric-visit variables, 2) details of transfer to adult care, 3) health status and health behaviors, and 4) health beliefs. The contribution of each block of variables was examined. A forward, stepwise approach used *P* < .15 criteria to include and *P* > .10 to remove variables; liberal cutoffs were used in the regressions, given that this is the first

study to examine correlates of successful transfer.<sup>63</sup> Similarly, *P* < .05 was used in univariate analyses.

Data from the medical record could have been missing due to patients being lost to follow-up or moving to another center. Patients living in Ontario and, more specifically Toronto, would be expected to have the most complete data. Thus, the bivariate analyses were repeated using only the 303 patients (84.2%) who were closest to a CACH center in Ontario (303 from the entire cohort; 194 who completed questionnaires) and again using data only from those who lived closest to the TCCCA (190 from the entire cohort; 120 who completed questionnaires). To facilitate interpretation of results, relations among certain predictor variables were also analyzed.

### RESULTS

A total of 170 of the 360 patients in this cohort (47%; 95% confidence interval [CI]: 42–52) had successfully transferred to adult care based on CACH center data. Most patients (89%) were seen at the TCCCA in Toronto. Of the patients who completed questionnaires, 27% had no cardiac appointments since age 18 (see Table 2).

#### Correlates of Successful Transfer to Adult Care

Among the cohort of eligible patients, successful transfer was related to living closest to a CACH center in Ontario, living at a closer distance to a CACH center anywhere in Canada, more pediatric cardiovascular surgeries, older age at last visit to the HSC, and having a recommendation from the pediatric cardiologist for CACH follow-up; recommendation of a time for adult follow-up did not significantly increase the likelihood of successful transfer beyond specifying adult follow-up with a CACH cardiologist (see Table 3).

Successful transfer to adult care was not related to age, nor was it related to patients' gender, educational attainment, residence in parents' home, average family income, primary diagnosis, or consenting to complete questionnaires (48.0% for patients who consented; 46.8% for patients who declined).

For patients who completed the questionnaires, results with the demographic, pediatric-visit, and details of adult-care variables were almost the same as with the entire cohort (see Table 3). In addition, successful transfer was related to reported frequency of adolescent cardiac appointments, patients' beliefs about where and when adult follow-up should take

**TABLE 2.** Transfer to Adult Care and Medical Care Since Age 18 Years

	%	<i>n</i>
Transfer outcomes*		
Successful transfer (seen at CACH center)	47.2	170
Registered at a CACH center but not yet seen	2.8	10
Unsuccessful transfer	50.0	180
Self-reported medical care since age 18†		
No medical care	7.7	18
Family physician or walk in clinic	19.7	46
General cardiologist	18.8	44
Pediatric cardiologist	3.8	9
Patient-reported CACH visit not on record	2.6	6
CACH center reported visit	47.4	111

\* Transfer outcomes based on data from the CACH centers for all 360 eligible patients.

† Self-reported medical care since age 18 is based on 234 patients who completed questionnaires.

**TABLE 3.** Bivariate Correlates of Successful Transfer From Pediatric to Adult Care Among the Entire Cohort of Eligible Patients and Those Patients Who Completed Questionnaires

Predictor Variables	Successful Transfer			
	All Eligible Patients		Patients Completing Questionnaires	
	OR	95% CI	OR	95% CI
Demographic Variables				
Ontario CACH center*	7.04	3.22–15.36	8.26	3.10–21.98
Greater distance to CACH center†	0.48	0.27–0.84	—	—
Pediatric-visit variables				
≥2 pediatric cardiovascular surgeries‡	2.82	1.81–4.40	2.59	1.49–4.51
Older age at last visit to HSC§	1.74	1.54–1.96	1.82	1.56–2.13
Patient reported frequency of adolescent visits				
Every 2 years vs every 3 years or less	—	—	6.42	1.83–22.46
At least once a year vs every 2 years	—	—	1.59	0.63–4.02
Details of adult care				
Adult follow-up recommendations¶				
CACH cardiologist but no time specified vs other physician or no details	8.01	4.72–16.41	14.35	6.13–33.62
CACH cardiologist with specified time for follow-up vs CACH cardiologist but no time specified	0.48	0.22–1.05	0.42	0.14–1.29
Patient believed follow-up should be at a CACH center#	—	—	4.73	2.59–8.65
Patient believed should be annual follow-up**	—	—	2.60	1.48–4.57
Health status and health behaviors				
Comorbidities††	—	—	2.45	1.37–4.38
CHD-related symptoms‡‡	—	—	1.92	1.01–3.64
Activity restrictions§§	—	—	2.49	1.40–4.41
Poorer physical functioning	—	—	2.68	1.52–4.73
Significant substance use¶¶	—	—	0.43	0.25–0.74
Dental antibiotic prophylaxis###	—	—	3.45	1.78–6.67
Attending CHD appointments without parents***	—	—	2.80	1.29–6.04
Health beliefs				
High risk of CHD complications†††	—	—	2.20	1.28–3.78
Adverse effects of not attending cardiology appointments†††	—	—	2.35	1.36–4.06
Low self-efficacy for attending cardiology appointments‡‡‡	—	—	2.23	1.25–3.96

For the entire cohort,  $n = 360$ ; for patients completing questionnaires,  $n$  varies due to missing data up to a maximum of 218 patients.

\* 0 indicates Outside Ontario; 1, within Ontario.

† 0 indicates <100 km; 1, 100 km. Distance to the nearest CACH center was not significantly related to successful transfer among patients who completed questionnaires.

‡ 0 indicates 0–1 surgery; 1, ≥2 surgeries.

§ Increasing age in 1-year intervals from age 13; age <13 grouped as one category.

|| 0 indicates every 3 years or less; 1, every 2 years; 2, at least once a year.

¶ 0 indicates no details, noncardiac or general adult cardiologist; 1, CACH cardiologist but no time for follow-up specified; 2, CACH cardiologist and some time for follow-up specified.

# 0 indicates no follow-up, family doctor, general, or pediatric cardiologist; 1, CACH cardiologist.

\*\* 0 indicates never, every 2 years or less often; 1, once a year or more.

†† 0 indicates no comorbid medical conditions; 1, at least 1 comorbid condition.

‡‡ 0 indicates no CHD symptoms; 1, at least one symptom.

§§ 0 indicates no activity restrictions; 1, some restrictions.

||| 0 indicates no physical limitations based on SF-36; 1, some physical limitations.

¶¶ 0 indicates no substance use; 1, at least one of the following behaviors in the past 30 days: smoking ≥2 days, binge drinking (5 drinks in a couple of hours), any marijuana use, and/or any illegal drug use.

### 0 indicates use of antibiotic <100% of dental appointments; 1, 100% of appointments.

\*\*\* 0 indicates attends appointment with parent or sibling; 1, attends alone or with spouse/peer.

††† 0 indicates not very or not at all likely; 1, at least somewhat likely.

‡‡‡ Efficacy for attending cardiology appointments rated from 0 (completely uncertain) to 10 (completely certain). 0 indicates 9 or 10; 1, <9.

place, and health status (ie, comorbid health conditions, CHD symptoms, restrictions on physical activity, or limitation in physical functioning). Substance use, dental antibiotic prophylaxis, and patients' independence in attending CHD appointments were also related to transfer, as were CHD-specific health beliefs (ie, risk of CHD complications, risk of adverse effects of not attending cardiac appointments, and self-efficacy for attending cardiac appointments).

Statistically significant analyses were repeated se-

lecting only those patients whose closest CACH center was in Ontario, with no change in results except that distance to the nearest center was no longer significant for analyses with data from the entire cohort. When analyses were repeated with data from patients whose closest center was the TCCCA, the magnitude of the relations was very similar, but 4 variables were no longer statistically significant (frequency of adolescent visits, comorbidities, CHD-related symptoms, and significant substance use). (Re-

**TABLE 4.** Blocked, Sequential Logistic Regressions Predicting Successful Transfer From Pediatric to Adult Care

Predictor Variables	All Eligible Patients (n = 360)			Patients Completing Questionnaires (n = 218)		
	OR	95% CI	P	OR	95% CI	P
Demographic and pediatric visits						
Ontario CACH center*	2.11	0.82–5.44	.121	4.20	0.95–18.54	.059
Closer distance to CACH center†	0.56	0.27–1.17	.126	—	—	—
≥2 pediatric cardiovascular surgeries‡	2.47	1.40–4.37	.002	1.40	0.51–3.86	.511
Older age at last visit to HSC§	1.29	1.10–1.51	.001	1.16	0.88–1.52	.291
Details of adult care						
Adult follow-up recommendations¶						
CACH cardiologist but no time specified vs other physician or no details	3.60	1.70–7.65	.001	9.31	2.25–38.62	.002
CACH cardiologist with specified time for follow-up vs CACH cardiologist but no time specified	0.51	0.23–1.14	.101	0.17	0.04–0.86	.031
Patient believed follow-up should be at a CACH center#	—	—	—	3.64	1.34–9.90	.011
Patient believed should be annual follow-up**	—	—	—	2.00	0.73–5.42	.176
Health status and health behaviors††						
Comorbidities‡‡	—	—	—	3.13	1.13–8.67	.028
Poorer physical functioning§§	—	—	—	2.50	0.94–6.64	.066
Significant substance use	—	—	—	0.18	0.07–0.50	.001
Dental antibiotic prophylaxis¶¶	—	—	—	4.23	1.48–12.06	.007
Attending CHD appointments without parents##	—	—	—	6.59	1.61–27.00	.009

\* 0 indicates outside Ontario; 1, within Ontario.

† 0 indicates <100 km; 1, 100 km. Distance to the nearest CACH center was not significantly related to successful transfer among patients who completed questionnaires and was not entered in the regression.

‡ 0 indicates 0–1 surgery; 1, ≥2 surgeries.

§ Increasing age in 1-year intervals from age 13; age <13 grouped as one category.

|| The block of details of adult-care variables added significantly to the regression equation: 1) total cohort (block  $\chi^2$  [2] = 27.96;  $P < .001$ ); 2) questionnaire patients (block  $\chi^2$  [4] = 50.18;  $P < .001$ ).

¶ 0 indicates no details, noncardiac or general adult cardiologist; 1, CACH cardiologist but no time for follow-up specified; 2, CACH cardiologist and some time for follow-up specified.

# 0 indicates no follow-up, family doctor, general, or pediatric cardiologist; 1, CACH cardiologist.

\*\* 0 indicates never, every 2 years, or less often; 1, once a year or more.

†† The block of health status and health behaviors added significantly to the regression equation: block  $\chi^2$  (5) = 39.42,  $P < .001$ .

‡‡ 0 indicates no comorbid medical conditions; 1, at least 1 comorbid condition.

§§ 0 indicates no physical limitations based on SF-36; 1, some physical limitations.

||| 0 indicates no substance use; 1, at least 1 of the following behaviors in the past 30 days: smoking ≥2 days, binge drinking (5 drinks in a couple of hours), any marijuana use, and/or any illegal drug use.

¶¶ 0 indicates use of antibiotic for <100% of dental appointments; 1, 100% of appointments.

## 0 indicates attends appointment with parent or sibling; 1, attends alone or with spouse/peer.

sults for all nonsignificant variables and analyses of data from both Ontario and Toronto patients are available on request.)

In multivariate analyses with data from the entire cohort, successful transfer was related to more pediatric cardiac surgeries, older age at last HSC visit, and recommendations for follow-up with a CACH cardiologist (see Table 4). For patients who completed questionnaires, the demographic and pediatric-visit variables were not statistically significant; only recommendation for follow-up with a CACH cardiologist was significant in the final regression equation. Patients who believed their cardiac follow-up should take place at a CACH center and had at least 1 comorbid medical condition were more likely to successfully transfer. Patients who used substances were less likely to transfer successfully. Finally, patients who always used dental antibiotic prophylaxis and those with greater independence in attending cardiac appointments were more likely to have had successful transfer. The block of health-belief variables (perceived risk of CHD complications, perceived risk of not attending CHD appointments, and self-efficacy for attending CHD appointments) was entered last but did not significantly add to the model.

### Relations Among Predictor Variables

Older age at last visit to the HSC was related to pediatric cardiologists' recommendations for adult follow-up (odds ratio [OR]: 3.47 [95% CI: 2.39–5.04] for each 1 year of age >14 years). When follow-up at a CACH center was documented in the medical chart, patients were 3.50 times more likely (95% CI: 1.91–6.42) to believe that their adult care should be at a CACH center compared with when no details for transfer were on file or a noncardiac or general cardiologist was recommended. However, patients' beliefs about time for adult follow-up were not related to documented recommendations ( $\chi^2$ : 1.1;  $P = .58$ ). The 4 health-status variables significantly related to transfer (ie, comorbidities, CHD-related symptoms, activity restrictions, and physical functioning) were combined (0 = 0 or 1 of these health problems; 1 = ≥2 problems), and relations with expectations for adult care were examined, as were pediatric cardiovascular surgeries. More pediatric surgeries related to the belief that adult care should be at a CACH center (OR: 2.46; 95% CI: 1.33–4.55); there was a trend toward relations with more health problems (OR: 1.99; 95% CI: 0.94–4.23). More pediatric surgeries (OR: 6.41; 95% CI: 3.12–13.17) and more health

problems (OR: 8.47; 95% CI: 2.89–24.75) were related to patient-rated need for annual adult care.

## COMMENTS

This is the first study to document the percent of young adults with a chronic illness who successfully transfer to adult care in a timely manner. Just less than half of this cohort of young adults with CHDs who, according to current practice guidelines, should be seen annually at a specialized adult CHD center successfully transferred to adult care. If the 14% of patients for whom a valid address could not be obtained had not transferred, assuming a 10% postcontact exclusion, the prevalence of successful transfer would be even lower (37%; 170 of 457). Patients consisted of an entire birth cohort of patients seen at the largest pediatric cardiac center in Canada, and outcome data were obtained on all eligible patients; thus, results were not influenced by patient selection bias. More than one quarter of patients reported no cardiac medical care since age 18. Will these patients experience an adverse event (eg, heart failure) or have poorer physical functioning compared with those who receive regular, ongoing adult care? Adherence to medical appointments has not been examined in relation to CHD outcomes. Expert consensus, high complication rates, premature mortality, and the fact that absence of symptoms is not a reliable indicator of cardiac function suggest that regular, specialized CHD care should confer the best chance for positive outcomes among these patients. The relation between adherence to medical appointments and outcomes should be examined for CHDs and other chronic diseases.

Successful transfer was related to documented pediatric cardiologists' recommendations and patients' beliefs that adult care should be at a CACH center. Having recommendations documented in the medical record was also related to patient beliefs. First, adult care needs to be discussed. No details related to adult care were reported in the pediatric records for 50% of the patients. It has been suggested that some pediatricians may be reluctant to discuss adult care.<sup>12</sup> Older age at last visit to the HSC was related to successful transfer and to having details for transfer recorded. Patients may discontinue care prematurely before pediatricians have the opportunity to discuss adult care. If so, recommendations that adult care be discussed in adolescence or even childhood are very appropriate.<sup>18</sup> An understanding of why patients drop out of pediatric care is needed. Second, patients must acquire appropriate beliefs about adult care. Individuals with comorbid medical conditions were more likely to transfer successfully, and health-status problems were related to expectations for adult care. Developmentally appropriate, staged discussions involving the patient, with and without parents, throughout adolescence may help patients acquire these beliefs and an understanding of the need for ongoing care. The relation between increased independence in attending pediatric appointments and successful transfer supports this recommendation and general recommendations that adolescents gradually increase responsibility for their health

care.<sup>18</sup> Other health care professionals (eg, nurses and psychologists) may have particular expertise in developing systematic programs to address these issues and/or greater training and time to engage in extended discussions. Overall, these data support the view that transition to adult care, a planned process of discussing and preparing for transfer to an adult health center, is important and should begin well before patients are transferred.

Patients who did not use substances excessively and always used dental antibiotic prophylaxis were more likely to have transferred successfully to adult care. Substance use is fairly common among young adults<sup>57</sup> and over half of this cohort used substances (eg, binge drinking) in the 30 days preceding assessment. What is not known is whether health risks associated with substance use are greater for patients with CHDs than other individuals. What is probably true is that avoiding substances reflects a positive health orientation, which in turn contributes to attending cardiac appointments. Many patients are not knowledgeable about endocarditis prophylaxis, one of the few CHD-specific health behaviors.<sup>64,65</sup> This type of specific knowledge may be more important than knowledge of cardiac anatomy or surgical history.<sup>18</sup>

Family income was surprisingly not related to successful transfer. Income and insurance coverage are likely more relevant in the United States than Canada. Family dysfunction has been related to poorer treatment adherence<sup>66</sup> but was not related to successful transfer, although the majority of patients lived with their parents. We measured general, not CHD-specific, family functioning. Disease-specific psychosocial measures have stronger relations than general measures with disease-specific outcomes.<sup>38</sup> Additionally, treatment of general family dysfunction improves family functioning but not disease outcomes.<sup>67</sup> The fact that CHD-specific beliefs (namely beliefs regarding adult care) but not general preferences for medical care were related to transfer supports this notion. A similar argument could be made for why mental health was not a significant predictor.

## Limitations and Implications

Almost one quarter (22%) of this cohort had not been seen since being at the HSC after they were 10 years old. It would have been ideal to have obtained recommendations for adult care from patients who moved and received pediatric care elsewhere. However, analyses using only patients closest to a CACH center in Ontario and only patients closest to the Toronto CACH center did not substantially alter the results.

Of eligible patients, 35% declined participation. The rate of successful transfer did not differ between these patients and those who completed questionnaires, and the relation between predictor variables available for the entire cohort of eligible patients (ie, demographics, pediatric cardiovascular surgeries, age at last HSC visit, and adult follow-up recommendations) and successful transfer was almost identical for the entire cohort and when analyzed only for those patients who completed questionnaires. Nev-

ertheless, individuals with more negative views related to CHDs or poorer health behaviors may have been less likely to participate. Thus, predictions based on these variables might differ if a greater proportion of the cohort had participated.

Patients with Down syndrome or developmental disability were excluded, because completion of the questionnaires and interviews used in the present study were not appropriate for individuals with intellectual limitations. Future studies should examine both the prevalence and correlates of transfer to adult care in this important subpopulation of individuals with CHDs.

Our data suggest that the longer patients receive care as adolescents, the more likely pediatric cardiologists are to make recommendations for adult care and patients are to have appropriate beliefs about adult care, in turn leading to successful transfer. If all adolescents needing specialized adult care continued to receive pediatric care throughout adolescence and were provided clear, simple information regarding where and when they should go for adult follow-up, dramatic improvements in transfer may occur. Nevertheless, almost one quarter of the patients believed adult care should be somewhere other than a CACH center despite opposite recommendations. For these patients, a single discussion of adult care during the final pediatric visit may be too little, too late. In addition to earlier discussions, multiple mechanisms such as referral letters and transition clinics are needed.<sup>18</sup> Similarly, patients engaging in multiple risky or poor health behaviors such as substance use may need an ongoing program of education, counseling, and treatment to make substantial changes in these behaviors, which hopefully would lead to successful transfer. There is considerable room to improve the numbers of young adults with CHDs who successfully transfer to adult care. These improvements might be achieved by simple changes in practice. The future health of adults with chronic conditions may depend on our ability to make these changes.

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