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Transfer of Adolescents With Congenital Heart Disease From Pediatric Cardiology to Adult Health Care

An Analysis of Transfer Destinations

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Objectives The transfer of adolescents with congenital heart disease from pediatric to adult care was examined. The aims were to investigate where these adolescents received adult-centered care, to determine the proportion of patients with no follow-up and with no appropriate follow-up after leaving pediatric cardiology, and to explore the determinants of no follow-up and no appropriate follow-up.

Background Even after successful treatment, many patients require lifelong cardiac surveillance by specialized practitioners. Although guidelines describe the most appropriate level of follow-up, this is not always implemented in practice.

Methods A descriptive, observational study was performed, including 794 patients with congenital heart disease examined and/or treated at a tertiary care center.

Results Overall, 58 of the 794 patients included (7.3%) were not in follow-up. Cessation of follow-up was found in 2 of 74 patients with complex (2.7%), 31 of 448 patients with moderate (6.9%), and 25 of 272 patients with simple (9.2%) heart defects. Moreover, 684 patients (86.1%) remained in specialized follow-up. According to international guidelines, 81 patients (10.2%) did not receive the minimal level of cardiac care. Multivariable logistic regression revealed that male sex and no prior heart surgery were associated with no follow-up. Male sex, no prior heart surgery, and greater complexity of congenital heart disease were associated with no appropriate level of cardiac follow-up.

Conclusions The proportion of patients in this study lost to follow-up was substantially lower than in other Western countries. Because only patient-related factors were examined with respect to loss to follow-up, further examination of patient-related, hospital-related, and healthcare-related determinants of lack of follow-up is needed.
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Congenital heart disease (CHD) is considered the most common birth defect, with an incidence of 0.8% in newborns (1). A substantial increase in life expectancy has been observed in past decades, with approximately 90% of children born with CHD surviving into adulthood (2). Despite this improvement, patients with CHD can experience residua or sequelae of the initial treatment they received. Therefore, these defects are considered "repaired" rather than "cured." Hence, even after successful primary treatment or surgery, many patients with CHD require lifelong cardiac surveillance by specialized practitioners (3–5).

International guidelines and consensus statements describe the most appropriate setting for follow-up of patients with CHD. During childhood, these patients are most appropriately followed up in pediatric programs. As they approach adulthood, a timely transfer to an adult congenital heart disease (ACHD) program is advocated (6–9). However, different levels of adult-centered care exist. For instance, guidelines categorize the level of ACHD care into 3 types: 1) specialist care; 2) shared care; and 3) nonspecialist care (6). Specialist care is follow-up given by specialized ACHD cardiologists and is provided mainly at tertiary care centers. Shared care is follow-up given by a general adult cardiologist in close collaboration with a CHD specialist. Nonspecialist care is follow-up given by a general or community cardiologist, or a general practitioner, with access to specialized care if needed (6).

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Guidelines describe which level of care is most appropriate for each type of heart defect (5,6,9). Except for patients with ligated and divided ductus arteriosus, all patients should continue to receive cardiac care from a specialized ACHD program, a local healthcare provider, or a collaboration between local and specialist providers (9). Patients with complex heart defects, such as cyanotic heart disease or transposition of the great arteries, should receive checkups every 6 to 12 months at a specialist center (5). Patients with moderate-complexity lesions, such as tetralogy of Fallot, atrioventricular septal defects, or coarctation of the aorta, should have follow-up visits every 1 to 2 years (5). This is preferably done at specialist centers (5) but can also be undertaken at shared care facilities if the CHD course is uncomplicated (6). Patients with simple heart defects, such as small atrial septal defects or patent ductus arteriosus, need medical checkups every 3 to 5 years, either in a nonspecialized setting or at shared care facilities (5,6).

When patients with CHD transition from adolescence to adulthood, they should be transferred to the most appropriate adult-focused facility without interruption (10). However, studies in Canada (11,12), Germany (4), the United Kingdom (13), and the United States (14) have demonstrated that 21% to 76% of adolescents with CHD are either lost to follow-up or experience lapses in care after leaving pediatric cardiology. To the best of our knowledge, no studies have comprehensively assessed the settings of care in which adolescents with CHD receive care after leaving pediatric cardiology. Therefore, the aims of the present study were: 1) to determine the transfer destinations of adolescents with CHD after leaving pediatric cardiology; 2) to determine the proportion of patients with no follow-up and with no appropriate follow-up after leaving pediatric cardiology; and 3) to explore the determinants of no follow-up and no appropriate follow-up.

Methods

Setting. As part of the SWITCH[2] (Self-Management and Well-Being Improvements by Transitioning Adolescents With Chronic Disorders in Hospital and at Home) research program (15), we conducted a descriptive, observational study at the University Hospitals Leuven (Leuven, Belgium). Belgium is a small country with a high population density. Belgium currently has 7 tertiary care centers for pediatric cardiology (16). The pediatric cardiology department of the University Hospitals Leuven cares for 27% of Belgian patients with CHD. At this center, it is standard practice to transfer patients from pediatric cardiology to adult-focused services when they reach 16 years of age, unless they are medically unstable. Because the pediatric CHD and ACHD programs are located in the same building, transferring patients and medical information is easy. Furthermore, both programs share 1 database for the clinical follow-up of patients. Although transfer from pediatrics to adult-focused care is well established, we do not have a formal transition program that prepares adolescents for the transfer and to take responsibility of their own care (17).

Abbreviations and Acronyms

ACHD = adult congenital heart disease
CHD = congenital heart disease
CI = confidence interval
OR = odds ratio

Study population. Eligible patients were adolescents with CHD, which was defined as structural abnormalities of the heart or intrathoracic great vessels that are actually or potentially of functional significance (18); were born between 1984 and 1988; and had one or more cardiac consults in pediatric cardiology between 2000 and 2004. The rationale for selecting these patients is that they had at least 1 outpatient visit at pediatric cardiology during adolescence, showing that they were not considered to be cured in childhood. Because they were 21 years of age or older in 2009, it could be assumed that all patients were cared for in adult-focused care facilities. We excluded patients who had died and those who had morphologically normal hearts, Wolff-Parkinson-White syndrome or cardiac arrhythmia without structural defects, noncardiac congenital defects, or pulmonary hypertension without structural anomalies. Heart transplant recipients were also excluded. On the basis of the center's database and outpatient appointment lists, we were able to identify all patients who met the inclusion and exclusion criteria. We included all 813 patients who were eligible for inclusion in this study. Nineteen patients had moved abroad and were excluded for statistical analysis because we could not obtain information about their current level of care. Hence, the final sample comprised 794 patients. Sociodemographic and clinical characteristics of this sample are presented in Table 1.

Definitions. To categorize patients according to their primary heart defect, we used a modified version of the hierarchy of heart defects developed by the CONCOR (CONgenital COR Vitia) project, an initiative to form a national registry of patients with CHD in the Netherlands (19). The modifications are detailed elsewhere (16). In Table 1, the heart defects are rank ordered according to the CONCOR classification scheme. Furthermore, using the criteria of Task Force 1 of the 32nd Bethesda Conference, we categorized patients according to the complexity of their heart defects (simple, moderate, and complex) (20).

Transfer destinations were defined on the basis of the 3 levels of CHD care described by Deanfield et al. (6): specialist care, shared care, and nonspecialist care. For the purposes of the present study, we subdivided specialist care into pediatric cardiology care, ACHD care, and care at satellite centers. The latter type of care refers to local hospitals that have a CHD cardiologist-operated outpatient clinic. Shared care is defined as care performed by general cardiologists who see patients with CHD but who send reports to specialist centers for passing on information and obtaining clinical advice, if needed. Finally, nonspecialist care is defined as care by general adult cardiologists who do

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Table 1 Sociodemographic and Clinical Characteristics of 794 Patients With CHD

Year of birth	
1984	147 (18.5)
1985	126 (15.9)
1986	175 (22.0)
1987	158 (19.9)
1988	188 (23.7)
Sex	
Male	421 (53.0)
Female	373 (47.0)
Primary CHD diagnosis	
Hypoplastic left-heart syndrome	1 (0.1)
Univentricular physiology	14 (1.8)
Tetralogy of Fallot	72 (9.1)
Pulmonary atresia with VSD	0 (0)
Pulmonary atresia without VSD	2 (0.3)
DORV	18 (2.3)
DILV	1 (0.1)
Truncus arteriosus	3 (0.4)
TGA	31 (3.9)
Congenitally-corrected TGA	4 (0.5)
Coarctation of the aorta	90 (11.3)
AVSD	48 (6.0)
ASD type I	10 (1.3)
Ebstein malformation	3 (0.4)
Pulmonary valve abnormality	94 (11.8)
Aortic valve abnormality	106 (13.4)
Aortic abnormality	14 (1.8)
Left ventricular outflow tract obstruction	22 (2.8)
ASD type II	60 (7.6)
VSD	118 (14.9)
Mitral valve abnormality	51 (6.4)
Pulmonary vein abnormality	10 (1.3)
Other	22 (2.8)
Complexity of primary CHD diagnosis	
Simple	272 (34.3)
Moderate	448 (56.4)
Complex	74 (9.3)
Prior interventions	
No intervention	301 (37.9)
Only catheter intervention	60 (7.6)
Only surgical intervention	379 (47.7)
Both catheter and surgical intervention	54 (6.8)
Distance from home to University Hospitals Leuven (km)	
0–49	235 (29.6)
50–99	407 (51.3)
100–149	125 (15.7)
150–199	26 (3.3)
>200	1 (0.1)

Values are n (%).

ASD = atrial septal defect; AVSD = atrioventricular septal defect; CHD = congenital heart disease; DILV = double-inlet left ventricle; DORV = double-outlet right ventricle; TGA = transposition of the great arteries; VSD = ventricular septal defect.

not send follow-up reports to specialist centers or care provided by general practitioners.

For inferential statistics, patients were noted as having no follow-up if they indicated that they were currently not in cardiac follow-up or if they could not be contacted by mail or phone. Minimal levels of care were determined according to the type and complexity of heart defects (5,6). The guidelines of Task Force 4 of the 32nd Bethesda Conference (5), with a few exceptions, are applied by our pediatric and ACHD cardiologists. Their expert opinions were used to determine the appropriate minimal level of care for our patients. Patients were noted as being in appropriate follow-up if they received follow-up in a setting that was minimally required or more specialized.

Procedure. For 676 patients, data on the setting of cardiac follow-up were obtained from our hospital information system. The remaining 137 patients received an information letter, including an informed consent form, requesting information about their current follow-up settings. We telephoned patients as a reminder. Nine patients could not be contacted by mail or telephone; they were untraceable. Sex, year of birth, primary CHD diagnosis, CHD complexity, prior cardiac surgery, prior catheter interventions, and distance from patients' homes to the University Hospitals Leuven were determined on the basis of the patients' medical records and additional data.

The institutional review board of the University Hospitals Leuven approved the study protocol. The study was performed in accordance with ethical standards, as described in the 2002 Declaration of Helsinki.

Statistical analysis. Data were analyzed using SPSS version 17.0 (SPSS, Inc., Chicago, Illinois). Nominal and ordinal data are presented as absolute numbers and percents. To determine sociodemographic and clinical variables associated with no follow-up and no appropriate follow-up, we performed multivariable logistic regression analysis using a backward stepwise method. Results are reported as odds ratios (ORs) and 95% confidence intervals (CIs). All tests were 2-sided, and a p value of 0.05 was used as a cutoff for statistical significance.

Results

Transfer destinations. Of the 794 patients included in the study, a total of 627 adolescents with CHD (79.0%) received follow-up at a tertiary care center. Of these, 613 (97.8%) were transferred to ACHD programs, and 14 (2.2%) were still in follow-up in pediatric cardiology (Fig. 1). In addition, 57 patients (7.2%) received follow-up at a satellite center. Hence, altogether, 86.1% of the patients continued to receive specialist care when they reached young adulthood. Fifty-two adolescents (6.5%) received cardiac follow-up from a general adult cardiologist. In 29 of the 52 cases (55.8%), cardiologists sent examination reports to CHD specialists; this type of follow-up was considered to be shared care.

Forty-nine patients (6.2%) had no cardiac follow-up after leaving pediatric cardiology, and 9 patients (1.1%) were untraceable. Hence, 58 of the 794 patients included (7.3%) were considered to be lost to follow-up. More specifically, 2 of the 74 patients with complex (2.7%), 31 of the 448

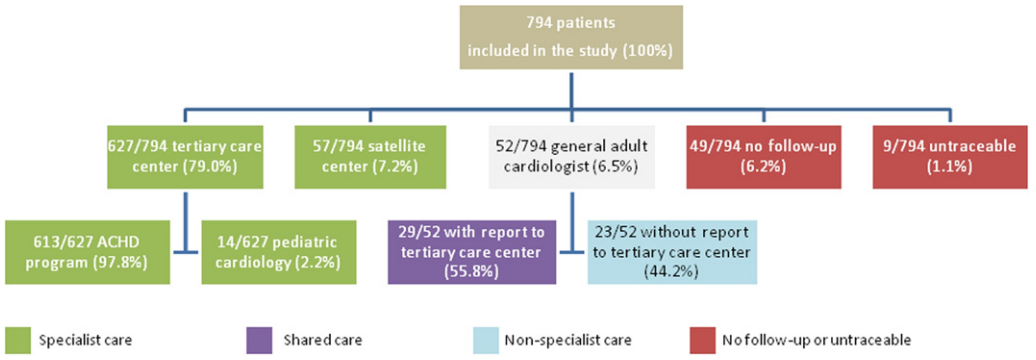

Figure 1 Transfer Destinations in 794 Patients With CHD

ACHD = adult congenital heart disease; CHD = congenital heart disease.

patients with moderate (6.9%), and 25 of the 272 patients with simple (9.2%) heart defects were no longer in cardiac follow-up.

Minimal level of cardiac care. On the basis of primary diagnosis and complexity of the congenital heart lesions, we subdivided patients into 3 groups relating to the minimal level of care they should receive. The first group consisted of patients who should receive specialist care exclusively (Table 2). This level of care can be performed at pediatric cardiology, ACHD programs, or satellite centers. In all, 225 patients (90%) received specialist care. Ten patients (4%) received shared care, 9 patients (3.6%) received nonspecialist care, 5 patients (2%) were no longer in follow-up, and 1 patient (0.4%) was untraceable. These latter levels of care were suboptimal for these patients.

Among 247 patients who should receive specialist or shared care, 215 patients (87%) received specialist care, and 7 patients (2.8%) received shared care (Table 3). Four patients (1.6%) received nonspecialist care, 17 patients (6.9%) were not in follow-up, and 4 patients (1.6%) were untraceable.

Of the 297 patients for whom nonspecialist care would be sufficient, 244 patients (82.2%) continued specialized follow-up, 12 patients (4%) received shared care, and 10 patients (3.4%) received nonspecialist care. Twenty-seven patients (9.1%) were not in cardiac follow-up, and 4 patients (1.3%) were untraceable (Table 4).

Altogether, our data revealed that 81 patients (10.2%) did not receive follow-up at the recommended level of care. These patients were considered as receiving no appropriate cardiac follow-up.

Factors associated with no follow-up and no appropriate follow-up. We investigated the association between 5 sociodemographic and clinical variables and no follow-up and no appropriate follow-up: sex, prior heart surgery, prior catheter intervention, complexity of heart defect, and distance from patients' homes to our hospital. Independent correlates of no cardiac follow-up after leaving pediatric cardiology were male sex (OR: 1.80; 95% CI: 1.02 to 3.17) and no prior heart surgery (OR: 5.97; 95% CI: 3.04 to 11.72). No appropriate level of cardiac follow-up after leaving pediatric cardiology was associated with male sex

Table 2 Congenital Heart Defects Requiring Specialist Care

Type of CHD	Specialist Care	Shared Care	Nonspecialist Care	No Follow-Up	Not Traceable
Hypoplastic left-heart syndrome	1				
Univentricular heart	14				
Pulmonary atresia without VSD	2				
DORV	16		2*		
DILV	1				
Truncus arteriosus	3				
TGA	28		2*		1*
Congenitally corrected TGA	3			1*	
Coarctation of the aorta	80	5*	2*	3*	
Aortic abnormality	11	2*		1*	
Tetralogy of Fallot	66	3*	3*		
Proportion of patients in each setting of follow-up	90.0% (n = 225)	4.0% (n = 10)*	3.6% (n = 9)*	2.0% (n = 5)*	0.4% (n = 1)*

*Patients who did not receive the minimal level of cardiac care.
Abbreviations as in Table 1.

Table 3 Congenital Heart Defects Requiring Specialist or Shared Care

Type of CHD	Specialist Care	Shared Care	Nonspecialist care	No Follow-Up	Not Traceable
AVSD	45		1*	2*	
ASD type I	7	1	1*		1*
Ebstein malformation	3				
Associated pulmonary valve abnormality	31	1	1*	3*	1*
Left ventricular outflow tract obstruction	19			3*	
VSD	29	2		3*	2*
Associated mitral valve abnormality	9			2*	
Pulmonary vein abnormality	10				
Isolated pulmonary valve abnormality	50	3	1*	3*	
Other	12			1*	
Proportion of patients in each setting of follow-up	87.0% (n = 215)	2.8% (n = 7)	1.6% (n = 4)*	6.9% (n = 17)*	1.6% (n = 4)*

*Patients who did not receive the minimal level of cardiac care.
Abbreviations as in Table 1.

(OR: 1.63; 95% CI: 1.01 to 2.63), no prior heart surgery (OR: 3.30; 95% CI: 1.88 to 5.77), and greater complexity of CHD (OR: 1.61; 95% CI: 1.04 to 2.49).

Discussion

Continuing follow-up is important for many patients with CHD. However, studies have shown that numerous patients are lost to follow-up or have lapses in care after leaving pediatric cardiology (4,11–14). Furthermore, not all patients receive the optimal level of care. Therefore, we investigated the destinations of transfer in adolescents with CHD, determined the proportion of patients with no follow-up and no appropriate follow-up after leaving pediatric cardiology, and sought correlates of no follow-up and no appropriate follow-up.

Comparing our findings with published data, the situation at our center appears to be substantially better than in other Western countries. To date, 5 studies have described the proportion of patients lost to follow-up and/or experiencing lapses in care after leaving pediatric cardiology (21). Reid et al. (11) investigated medical care in 360 patients age 19 to 21 years with complex CHD. These patients were followed up in pediatric cardiology at the Hospital for Sick Children in Toronto, Ontario, Canada, before the age of 18 years. The investigators defined successful transfer as patients attending ≥1 appointment at a Canadian ACHD center. In this study, 53% of the patients did not successfully transfer, and >25% had no cardiac appointments after the age of 18 years.

At the German Heart Center in Munich, Germany, Wacker et al. (4) evaluated the rate and outcomes of adults with CHD lost to follow-up. Patients were selected from the CHD program registry (n >10,500). This population included a broad spectrum of CHD. Loss to follow-up was defined as patients' failing to return for follow-up visits to their center for >5 years. The investigators found that >76% of patients were lost to follow-up.

In another study, de Bono and Freeman (13) assessed 59 patients with coarctation of the aorta. This study was performed in the United Kingdom at a local ACHD clinic without on-site cardiothoracic surgery or pediatric cardiology facilities. Patients who were in follow-up in the ACHD clinic at the time of the study, but who were not being seen at other cardiac clinics for a period of ≥2 years, were considered lost to follow-up. Thirty-nine percent of the patients had ≥1 episode of loss to follow-up.

Yeung et al. (14) conducted a study in Denver, Colorado, that determined the proportion of patients (with moderate or complex heart defects) who experienced lapses in medical care after leaving pediatric cardiology. A lapse in care was defined as a >2-year interval between leaving pediatric cardiology and presentation at the ACHD clinic. In 63% of

Table 4 Congenital Heart Defects for Which Nonspecialist Care Is Sufficient

Type of CHD	Specialist Care	Shared Care	Nonspecialist Care	No Follow-Up	Not Traceable
Isolated aortic valve abnormality	47	2	4	2*	
Associated ASD type II	27	1	1	2*	
Isolated ASD type II	27	1		1*	
VSD repaired without residua	72	2	2	4*	2*
Isolated mitral valve abnormality	25	2	2	9*	2*
Associated aortic valve abnormality	40	3	1	7*	
Other	6	1		2*	
Proportion of patients in each setting of follow-up	82.2% (n = 244)	4.0% (n = 12)	3.4% (n = 10)	9.1% (n = 27)*	1.3% (n = 4)*

*Patients who did not receive the minimal level of cardiac care.
Abbreviations as in Table 1.

patients, lapses of care were observed, with a median interval duration of 10 years.

Mackie et al. (12) conducted a population-based investigation in Quebec, Canada, of 643 patients diagnosed with CHD before 6 years of age and currently 22 years old. Lack of follow-up, defined as the absence of an outpatient assessment by a cardiologist, was retrieved from the physician billing database. This study revealed that 61% of the patients failed to receive cardiac follow-up after their 18th birthdays. Subgroup analyses showed that 47% of patients with moderate or complex heart defects (mild defects were excluded) were lost to follow-up after their 18th birthdays, whereas 21% of adult patients with complex lesions (mild and moderate defects were excluded) were lost to follow-up.

Generally, a wide variation in percents of patients lost to follow-up or those with lapses of care has been observed. However, these data are not comparable, because the studies differed substantially in terms of definition of loss to follow-up, study population, inclusion criteria, recruitment setting (pediatric cardiology, ACHD clinic, or population based), data collection methods (database or retrospective evaluation), and follow-up period. This likely resulted in underestimation and overestimation of the proportions of patients lost to follow-up. For example, de Bono and Freeman (13) and Yeung et al. (14) recruited patients at ACHD clinics. By doing so, they underestimated the problem of loss to follow-up, because patients not under medical surveillance were excluded in their studies. In contrast, Wacker et al. (4) included all patients recorded in their center's registry and considered patients to be lost to follow-up if they did not have checkups at that specific center. Consequently, they probably overestimated loss to follow-up, because a substantial number of patients with mild defects may not have needed ongoing cardiac follow-up, and some patients received cardiac follow-up at other centers.

Regardless of the limited comparability across these studies, our study demonstrated a considerably lower proportion of loss to follow-up. There are several explanations. First, at our center, pediatric cardiology and an ACHD program are located in the same building. Hence, patients do not have to go to another hospital when being transferred to adult care. Second, pediatric and ACHD cardiologists at our center use the same medical records, hospital information system, and database. This facilitates the transfer of medical information. Third, to keep patients under medical surveillance, our clinic sends outpatient visit reminders to patients, according to the proposed frequency of follow-up visits. Nonresponding patients will receive up to 3 reminders. Fourth, Belgium has a compulsory health insurance system, covering almost the entire population. Therefore, noninsurance or underinsurance is no barrier for patients wanting to obtain the care needed. Fifth, there is no mandatory general practitioner gate-keeping system in Belgium, resulting in easy access to tertiary care, which increases the accessibility of CHD care. Finally, Belgium is a small country with a high population density. Hence, the distances from patients' homes to specialized centers are relatively short. In our sample, 80% of the patients lived <100 km (<62 mi) from our hospital.

To what extent these factors affected our findings is unknown. However, obviously not only patient-related factors but also healthcare system–related and hospital-related factors have an impact on successful continuation of cardiac follow-up when patients reach adulthood. Indeed, the availability and structure of CHD programs will have an impact on how care is provided (22,23). To address this issue, we are currently preparing the INTERCHANGE (INTERnational study on the Continuation of Heart health checks in young Adults with coNGEnital heart disease) study, an international study on healthcare-related, hospital-related, and patient-related determinants of lack of cardiac follow-up in adulthood. This will be an observational study using a multilevel approach, with data collection at 3 levels: country, center, and patient. Across Europe and North America, >20 centers will participate, including about 7,500 patients.

In the present study, we focused on the minimal level of care. We found that 10.2% of our patients did not receive follow-up at the minimally recommended level. However, we also observed that the level of care exceeded the guidelines in many patients (5). For instance, in the group of patients for whom nonspecialist care is sufficient (Table 4), 86.3% of patients received specialist or shared care. If the ACHD program is saturating, there would be an opportunity to discharge patients with mild heart defects to lower levels of care. So far, we have not done so, because our pediatric cardiology and ACHD programs are located in a teaching hospital. In terms of training of cardiology fellows, it is considered to be appropriate to have exposure to the entire spectrum of CHD.

Study limitations. First, this study was conducted at 1 tertiary center with a specific structure and located in a particular healthcare system. Thus, our results are not generalizable. Second, this study mainly applied the Task Force 4 recommendations for cardiac follow-up (5). These recommendations are not completely consistent with, for instance, European guidelines (6). Application of European guidelines would likely result in different findings. Third, only patient-related correlates of no follow-up and no appropriate follow-up were investigated, leaving healthcare system–related and hospital–related factors unaddressed. The planned INTERCHANGE study, however, will address these factors.

Conclusions

Only 7.3% of our patients with CHD were no longer in cardiac follow-up after leaving pediatric cardiology. Of the patients with complex, moderate, and simple CHD, 2.7%, 6.9%, and 9.2%, respectively, were no longer in follow-up. According to international guidelines, 10.2% of our patients

did not receive follow-up at the minimally recommended level. No follow-up was associated with male sex and no prior heart surgery. No appropriate follow-up was correlated with male sex, no prior heart surgery, and greater complexity of CHD. Our results are substantially better than those in other Western countries. Firm explanations for the observed differences will be determined in our future study of healthcare-, hospital-, and patient-related determinants.

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