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ORIGINAL ARTICLE

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Short-term outcomes following implementation of a dedicated young adult congenital heart disease transition program

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Abstract

Objective: Transition from pediatric to adult care is a critical time for patients with congenital heart disease. Lapses in care can lead to poor outcomes, including increased mortality. Formal transition clinics have been implemented to improve success of transferring care from pediatric to adult providers; however, data regarding outcomes remain limited. We sought to evaluate outcomes of transfer within a dedicated transition clinic for young adult patients with congenital heart disease.

Design, Setting, and Patients: We performed a retrospective analysis of all 73 patients seen in a dedicated young adult congenital heart disease transition clinic from January 2012 to December 2015 within a single academic institution that delivered pediatric and adult care at separate children's and adult hospitals, respectively.

Intervention and Outcome Measures: Demographic characteristics including congenital heart disease severity, gender, age, presence of comorbidities, presence of cardiac implantable electronic devices, and type of insurance were correlated to success of transfer. Rate of successful transfer was evaluated, and multivariate analysis was performed to determine which demographic variables were favorably associated with transfer.

Results: Thirty-nine percent of patients successfully transferred from pediatric to adult services during the study period. Severe congenital heart disease (OR 4.44, 95% CI 1.25-15.79, $P = .02$) and presence of a cardiac implantable electronic device (OR 4.93, 95% CI 1.18-20.58, $P = .03$) correlated with transfer. Trends favoring successful transfer with presence of comorbidities and private insurance were also noted.

Conclusions: Despite a dedicated transition clinic, successful transfer rates remained relatively low though comparable to previously published rates. Severity of disease and presence of implantable devices correlated with successful transfer. Other obstacles to transfer remain and require combined efforts from pediatric and adult care systems, insurance carriers, and policy makers to improve transfer outcomes.

KEYWORDS
adult congenital heart disease, health policy, transitional care

1 | INTRODUCTION

Due to advances in diagnosis and treatment, 90% of children with all forms of congenital heart disease (CHD) now routinely survive into adulthood.[1,2] However, many children's hospitals do not see patients aged over 18 or 21 years. This practical limitation necessitates appropriate transfer of care from pediatric to adult health care settings. Furthermore, the need to ensure that young adults with chronic diseases

develop independence and the ability for self-care and advocacy urgently necessitates the development of programs to ensure smooth transition of care, as supported by joint statements from the American Academy of Pediatrics, American Academy of Family Physicians and the American College of Physicians as well as by the American Heart Association (AHA) and American College of Cardiology (ACC).[1,3–5]

Formal transition clinic programs have been devised to address the needs of young adult patients with CHD and to help overcome obstacles to successful transfer of care. The outcomes of their implementation and integration in the care of these patients as well as specific limitations and areas for improvement of these programs remain poorly understood. We sought to evaluate current outcomes of a dedicated young adult CHD transition clinic with attention to specific variables and their correlation with transfer success.

2 | METHODS

A retrospective analysis of all patients seen in our institution's formal young adult CHD transition clinic from January 2012 to December 2015 was completed after receiving Institutional Review Board approval. Demographic characteristics analyzed included patient age, gender, CHD severity (based on the AHA/ACC 32nd Bethesda conference recommendations), presence of comorbidities, presence of a cardiac implantable electronic device (CIED), and type of insurance coverage.

At our academic institution, pediatric and adult CHD care services are delivered in separate, freestanding and independent hospital facilities roughly eight miles apart. A formal transition program has been in place with patients' primary pediatric cardiologists initiating an educational process with patients and their families surrounding topics of transition of care beginning at the age of 12 years. In 2012, a formal young adult CHD transition clinic was implemented. This clinic operates monthly at the referring children's hospital, which has an upper age limit for care at the age of 21 years. Patients are referred by their primary pediatric cardiologist aged as early as 18 years (or earlier if insurance coverage permits earlier transfer of care). During the transition clinic visit, each patient meets with the transition care team, which is comprised of a nurse care manager, social worker and the adult congenital heart disease (ACHD) physician specialist from the adult hospital. The team assesses the patient's readiness for transition and provides resources to help navigate the physical transfer of care from the children's hospital to the adult hospital. Neither formal readiness checklists nor patient knowledge quizzes were initially used (both of these tools have begun to be implemented though their utility is outside the scope of this study). Comprehensive review of medical records, current medical needs and conditions, and clinical examination are performed by the ACHD physician specialist, and general rapport is established. Patients seen in the transition clinic are then scheduled for appointments in the ACHD clinic at the adult hospital campus with this same ACHD provider

All patients seen in the transition clinic were included in the study population; patients without structural congenital heart disease were excluded from statistical analysis. Those initially referred but never seen for a visit were also excluded. Transfer of care was defined as successful if patients seen in the transition clinic were subsequently seen on at least one occasion in the ACHD clinic at the adult hospital. Transfer success was calculated, and univariate and multivariate regression analyses were performed to assess impact of the abovementioned demographic variables on transfer outcomes.

3 | RESULTS

A total of 86 visits were scheduled, and 73 patients were seen in the transition clinic during the study period (15% no-show rate). Among these patients, 49% were male and average age at the time of transition clinic visit was 20 years. The vast majority of patients (85%, 62/73) had moderate or severe forms of CHD. Table 1 outlines the different CHD lesions, and Figure 1 categorizes the clinic population by CHD severity. Over half of the overall cohort (62%, 45/73) had noncardiac comorbidities, the spectrum of which is summarized in Table 2. Among patients with comorbidities, genetic syndromes were the most commonly encountered conditions. Nearly half of the patients with comorbidities had defined genetic conditions including Down syndrome (15), 22q11 chromosomal disorders (4), Turner syndrome (2), and Marfan and Kabuki syndromes (1 each). An additional nine patients had metabolic and developmental disorders that were not definitively attributed to an underlying genetic etiology. Three patients experienced endocarditis in the setting of previously repaired or unrepaired CHD with additional clinical sequelae. Most patients (75%, 55/73) had California state subsidized public Medicaid insurance coverage (Medi-Cal). Of those with public insurance, 56% (31/55) had pure Medi-Cal coverage, while 44% (24/55) had a Medi-Cal managed care (HMO) plan. Nearly 22% of patients had CIEDs, the majority being pacemakers. Patients were generally seen only once in the transition clinic.

Of the 73 patients seen, six patients were excluded from the multivariate analysis given the lack of primary structural CHD (one with sick sinus syndrome, two idiopathic heart block, one idiopathic premature ventricular contractions, one aborted sudden cardiac death without defined etiology, and one with Pompe's disease but no cardiac disease). Of the remaining 67 patients with structural CHD, 39% (26/67) successfully transferred their care following their transition clinic visit. Univariate analysis demonstrated no significant difference in demographic variables between patients who successfully or unsuccessfully transferred care. The addition of multivariate linear regression analysis (Figure 2) showed significant association between successful transfer and the presence of CIEDs (OR 4.93, 95% CI 1.18–20.58, $P = .03$) and severe versus mild/moderate CHD (OR 4.44, 95% CI 1.25-15.79, $P = 0.02$). A trend toward significance was seen with the presence of comorbidities (OR 2.51, 95% CI 0.70-8.99, $P = .16$) and private versus public insurance coverage (OR 1.99, 95% CI 0.44-8.93, $P = 0.37$).

4 | DISCUSSION

Our short-term data following implementation of a dedicated young adult CHD transition program demonstrates somewhat disappointing

TABLE 1 Spectrum of CHD severity among patients seen in young adult CHD transition clinic

CHD severity	Defect	Number of patients
No CHD	Primary arrhythmia	5
	Pompe's disease	1
Mild CHD	Bicuspid aortic valve	2
	VSD	2
	ASD	1
Moderate CHD	AVC	9
	TOF	8
	ASD/VSD	4
	Complex aortic root dilation	4
	Coarctation of aorta	3
	TOF/AVC	3
	Complex VSD	2
	PAPVC	2
	Mitral stenosis	2
	Subaortic stenosis	1
Severe CHD	Tricuspid atresia	4 (total)
	s/p Fontan	2
	s/p Glenn	1
	s/p 1.5-ventricle repair	1
	PAIVS	3 (total)
	s/p Fontan	1
	s/p biventricular repair	2
	DORV	2 (total)
	s/p Fontan	1
	s/p biventricular repair	1
	IAA/VSD	2
	MAPCAs	2
	DILV s/p Fontan	1
	Ebstein's anomaly s/p Fontan	1
	Eisenmenger's syndrome (VSD)	1
	HLHS s/p Fontan	1
	Hypertrophic cardiomyopathy	1
	Critical AS s/p Ross procedure	1
	Shone syndrome	1
	TOF/AVC/mechanical MV	1
	D-TGA s/p arterial switch	1
	Truncus arteriosus, type I	1
	Unbalanced AVC s/p Fontan	1

Abbreviations: AS, aortic stenosis; ASD, atrial septal defect; AVC, atrioventricular canal; D-TGA, dextro-transposition of the great arteries; DILV, double inlet left ventricle; DORV, double outlet right ventricle; HLHS, hypoplastic left heart syndrome; IAA, interrupted aortic arch; MAPCAs, major aortopulmonary collateral arteries; MV, mitral valve; PAIVS, pulmonary atresia with intact ventricular septum; PAPVC, partial anomalous pulmonary venous connection; TOF, tetralogy of fallot; VSD, ventricular septal defect.

outcomes for overall transfer success. Variables that were significantly associated with successful transfer included severe CHD type and the presence of CIEDs. Though not statistically significant, the presence of comorbid conditions and private insurance coverage also appeared to favorably influence successful transfer outcomes.

Providing appropriate transition services and transfer of care are important yet difficult for providers to deliver to adolescent and young adult patients living with chronic diseases. While transfer of care is considered the single event of officially leaving pediatric care and establishing adult care, transition refers to a planned process that

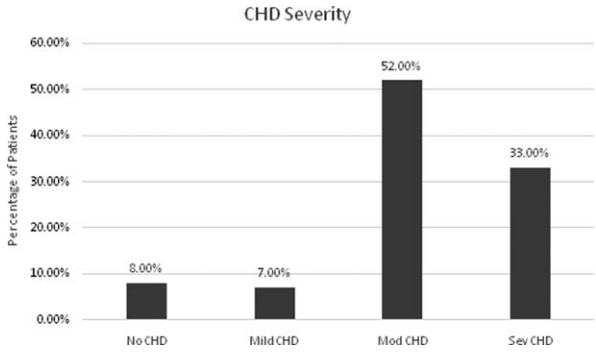

FIGURE 1 Categorization of CHD severity in the young adult CHD transitional clinic. CHD, congenital heart disease; Mod, moderate; Sev, severe

addresses needs and obstacles and prepares patients and families for formal transfer of care.[4] It is well documented that the lack of appropriate transition leads to loss of follow-up and lapses in care. Specific to CHD care, Reid et al. first examined rates of successful transfer of care among young adults with CHD and noted a successful transfer rate from pediatric to adult institutions of 47%.[6] In contrast, Wacker et al. found that 76% patients were lost to follow-up (defined as no follow-up appointment within 5 years from last appointment).[7] Yeung et al. also showed that 63% of patients presenting for their first ACHD visit had lapses in care of 2 years or greater.[8] Similarly, Mackie et al. found that 61% of patients lacked follow-up with a cardiologist after they reached the age of 22 years.[9] The highest reported successful transfer rate was reported by Goossens et al. (86%). who credited this high

TABLE 2 Noncardiac comorbidities in patients seen young adult CHD transition clinic

Noncardiac comorbidities	Number of patients
Genetic syndromes	
Trisomy 21	16
22q11 deletion	4
Kabuki	1
Marfan	1
Pompe's	1
Proteus	1
Turner	1
Other not otherwise specified	5
Other syndromes	
Spina bifida	2
Heterotaxy syndrome	1
Developmental/psychiatric	10
Other organ systems	
Endocrine	5
Musculoskeletal	5
Neurologic	4
Ear, nose, throat	3
Gastrointestinal	3
Pulmonary	3
Renal/genitourinary	3
Hematologic/oncologic	2
Hypertension	2
Obesity	2

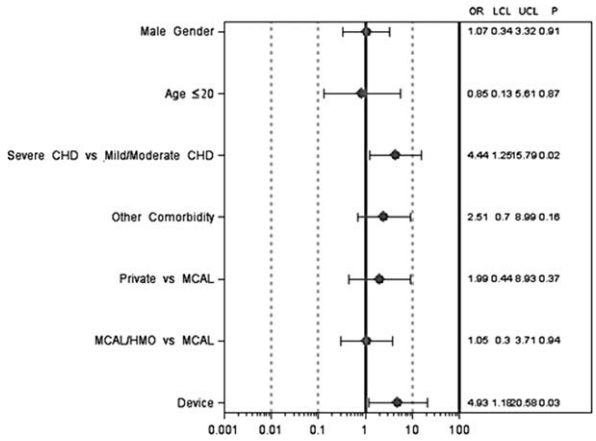

FIGURE 2 Multivariate analysis of patients with successful transfer to ACHD clinic. CHD, congenital heart disease; MCAL, Medi-Cal; OR, odds ratio; LCL, lower confidence limit; UCL, upper confidence limit

degree of success to the unique logistics of a single database of all CHD patients, earlier initiation of transfer at the age of 16 years and a single and shared location of care for pediatric and adult patients.[10] In 2013, the multicenter HEART-ACHD study found gaps in care (defined as >3 years without follow-up) in 42% of patients presenting for the first time to one of 12 North American ACHD referral centers overall, with a range of 22%-61% at individual centers across all geographic parts of the continent.[11] Finally, in 2016, Bohun et al. found a 34% successful transfer rate, despite synchronizing factors thought to facilitate a smooth transition at the Oregon ACHD care program.[12]

Previously reported data, along with our outcomes presented here, indicate that pediatric-to-adult CHD transfer of care remains incredibly challenging and requires improvement. The ramifications of failed transfer are quite concerning. Yeung et al. noted that patients lost to follow-up were more likely to be symptomatic, receive new cardiac diagnoses, and need urgent catheterization upon re-presentation to a provider.[8] Furthermore, Gurvitz et al. found an increased likelihood of emergency department (ED) visits among CHD patients during the young adult transition period and that more than one-third of ACHD admissions originated from the ED, nearly doubling that of adolescent CHD patients.[13] More recently, Agarwal et al. found that ED visits continue to increase for the ACHD population with an increased rate of admissions for even simple CHD lesions.[14] In contrast, among ACHD patients who received recommended care in accordance with the Canadian Cardiac Society and the AHA/ACC 32nd Bethesda guidelines, Mylotte et al. showed reduction in morbidity and mortality.[15]

4.1 | Transfer rates

Our successful transfer rate of 39% (26/67) was low, though not significantly dissimilar from previously published rates. The exact reason for loss of follow-up is unknown, but it is likely that many patients may be receiving care at other ACHD programs within the region, with adult cardiologists or solely with primary care providers.

4.2 | CHD severity

In our study, patients with severe forms of CHD were more likely to be successfully transferred to the ACHD clinic when compared to those with other CHD types. This phenomenon, also seen in other referenced studies, is likely due to the fact that those with severe CHD are likely to be followed with greater frequency during early childhood and adolescence, which positively reinforces the necessity for ongoing care in adulthood.[8,11,12] The process of transitioning care likely begins at an earlier age in these individuals, and these patients and their families are likely more informed and prepared regarding the importance of long-term ACHD care as well. Those with mild CHD, on the other hand, tend to be followed less frequently as outpatients and may be asymptomatic, both of which may negatively impact the eventual establishment of CHD care in adulthood.

4.3 | Cardiac implantable electronic devices (CIEDs)

The presence of CIEDs and association with successful transfer has not been cited in prior studies, but like those patients with severe disease, patients with CIEDs may have more frequent visits with their doctors for symptoms and/or routine device care and interrogation. Moreover, these patients may overlap with patients with severe CHD, giving them another reason for more frequent visits.

4.4 | Comorbidities

Though not statistically significant, there was a trend toward more successful transfer among patients with comorbid conditions. Noncardiac conditions and medical problems that co-exist with CHD as part of genetic syndromes result in substantial complexities that may warrant frequent follow-up both in childhood and adolescence. Similar to the impact of severe forms of CHD, comorbidities likely drive discussions of transitioning care and the importance of continuing care in adulthood to occur at earlier ages and at more frequent intervals, which likely favors successful transfer of care in young adulthood. Acquired comorbidities commonly seen in adult medicine such as hypertension, hyperlipidemia, and obesity that affect young adult CHD patients might also serve as primary health concerns that motivate referral to ACHD specialists.[16]

4.5 | Insurance

A trend was noted in our experience between the presence of public insurance coverage and unsuccessful transfer of care. Further subanalysis of the different public plans—state subsidized with or without managed care (Medi-Cal versus Medi-Cal HMO)—demonstrated no advantage to either. Bohun et al. also found that insurance status correlated with successful follow-up in their study.[12] The impact of private versus public insurance on transfer success may relate to differences in access to care at appropriate ACHD referral centers due to contracts and/or referral flexibility. Perhaps contracts between centers that offer ACHD care and private insurance carriers are more likely to exist compared to contracts with public, state-subsidized insurance carriers.

Furthermore, private insurance plans may allow more flexibility in referral to subspecialists.

At present, many insurance companies' plans, especially public ones, fail to recognize ACHD patients as distinct from other patients needing general cardiology referral. As such, while referral to an in-network general adult cardiologist is typically provided, referral to an ACHD specialist is denied. This denial could result in delay of ACHD-appropriate care and increased urgent and emergent care visits. Centers equipped to care for ACHD patients and patient advocacy groups must educate insurance companies and policy makers on the unique needs of the ACHD population and the importance of prompt transition to established ACHD centers for lifelong follow-up care as outlined in the ACC/AHA guidelines.[1]

4.6 | Further importance of CHD transition programs

It is well recognized that the cost of managing ACHD patients has been rising in recent decades. Opotowsky et al. reported a dramatic doubling of ACHD-related hospital admissions (35 992 admissions in 1998 to 72 656 admissions in 2005), corresponding to an increase in mean hospital charges per admission from $19 186 to $43 496.[17] In a separate study, Agarwal et al. reported an 82% increase in ACHD-related hospital admissions nationwide between 2003 and 2012 with increasing average lengths of stay linearly related to CHD severity. Of note, an increasing number of admissions were on an emergent basis.[18] Finally, Lu et al. noted a significantly higher increase in ED initiated hospitalizations (35%) among young ACHD patients with public compared to private insurance (27%).[19] These high and rising costs associated with emergent care and hospitalizations in young ACHD patients could be mitigated with greater priority and support of preventive and maintenance care services provided by formal transition programs and appropriate referral to ACHD care centers.

In a recent study on barriers to ACHD care, Fernandes et al. found that the perception of a lack of a qualified adult provider was the third most common barrier behind attachment to the provider on the part of the patient and parent.[16] The lack of patients' and providers' knowledge of qualified ACHD providers highlights the need for more robust transition programs so that pediatric centers can be appropriately linked with qualified ACHD providers to which care can be transferred as patients reach adulthood. In a separate survey of general adult cardiologists, 95% reported seeing ACHD patients themselves, including patients with the most severe forms of CHD, but only 28% caring for severe CHD consulted with ACHD specialists.[20] These survey results are alarming given the evidence highlighting the highly specialized care that ACHD patients require. Firm support for widespread implementation of CHD transition clinics can also create an infrastructure for the gradual transfer of care for young adult CHD patients followed by community pediatric and adult providers who may otherwise refer to general adult cardiologists who do not have special ACHD training or board certification. Support for transition programs is also required on the part of patients and their families, providers, and insurance carriers within a general framework of understanding that ACHD care is best delivered through qualified ACHD centers staffed with trained ACHD providers.

Despite having an organized transition clinic and qualified ACHD care, our program's successful transfer rate remained relatively low. However, this result is similar to the experience reported by Bohun et al. where patients were transferred from pediatric to adult providers within the same center, but without a formal transition clinic to facilitate transfer.[12] Thus, while having qualified providers and accredited programs are necessary, as single factors they are insufficient to guarantee successful transfer. Our results, along with the published experiences at other centers, reveal that other elements besides formal transition programs and qualified providers can either facilitate or limit the transfer process. These elements may include (1) case management that can support and provide ongoing patient and family education regarding long-term and individualized CHD care needs, (2) services that address psychosocial and socioeconomic factors that may hinder transfer, and (3) policies and guidelines directed toward insurance providers and medical institutions that improve access of recommended and appropriate ACHD care services to patients that require them.

Thus, in addition to the implementation of transition readiness checklists and assessment of patient knowledge, what may be even more important for patient outcomes is for transition programs to emphasize the hiring of dedicated staff that can longitudinally plan and prepare the transition and transfer processes with patients as well as lobbying efforts that promote public policy changes and insurance regulations to facilitate patient transfer from the pediatric to adult health care setting. The spectrum and volume of medical, psychosocial, and organizational issues involved in the transition and transfer process require an appropriately staffed team to adequately equip patients and families and appropriately prepare them for ongoing ACHD care. From our study findings, in addition to ACHD certified cardiologists and a nurse practitioner, comprehensive transition programs at minimum should be equipped with a dedicated case manager and insurance navigator, particularly if the pediatric and ACHD programs are in separate locations. Direct and prompt access to a social worker and psychologist should also be available. Finally, education surrounding long-term ACHD care needs and the transition/transfer process should be emphasized at an earlier age (no later than 12 years depending on developmental status), especially to patients with mild and moderate forms of CHD who, based on our results, are at a higher risk of failing to transfer appropriately and potentially being lost to follow-up due to their less frequent visits and overall less exposure to care.

5 | LIMITATIONS

The current study is limited by its small patient cohort size and retrospective design. Prior to the implementation of the formal transition program, the rate of successful transfer of young adults with CHD was not tracked and, therefore, could not be compared to outcomes from our program. As we have self-evaluated our data, we have implemented and/or plan to implement changes and established

practices that we expect will improve our rate of successful transfer, including implementation of transition readiness questionnaires like the Transition Readiness Assessment Questionnaire (TRAQ), patient knowledge quizzes of disease understanding, and patient-centered transitions notebooks to facilitate ownership of care among our young adults. The study was not designed to be able to evaluate the impact of these changes prospectively.

Several patients were lost to follow-up due to lapses in communication. This limited our ability to track outcomes as far as establishment of care with other local ACHD providers, general adult cardiologists, adult primary care, or no care at all. Finally, this study was conducted at a single institution with physically separate pediatric and adult cardiac centers, and may not reflect the experience at other institutions with different configurations of their pediatric and adult programs.

6 | CONCLUSIONS

Ensuring smooth transition of care for patients transferring from pediatric to adult congenital cardiology centers remains a difficult task. Further emphasis on this process by adult congenital providers and the entire pediatric and adult health care system—including case management, ancillary support services, and insurance companies—is necessary to mitigate emergent health care utilization by young ACHD patients and prevent poor outcomes in adulthood.

CONFLICT OF INTEREST

No conflicts of interest or grant funding to disclose.

AUTHOR CONTRIBUTIONS

All authors read and approved the final version of the manuscript.

Conceptualized the study, carried out the initial analyses, drafted the manuscript: Vaikunth

Conceptualized the study, critically reviewed and revised the manuscript: Chang, Williams, Uzunyan, Barton

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REFERENCES

[1] Warnes CA, Williams RG, Bashore TM, et al. American College of Cardiology, American Heart Association Task Force on Practice Guidelines (Writing Committee to Develop Guidelines on the Management of Adults With Congenital Heart Disease), American Society of Echocardiography, Heart Rhythm Society, International Society for Adult Congenital Heart Disease, Society for Cardiovascular Angiography and Interventions, Society of Thoracic Surgeons. *J Am Coll Cardiol*. 2008;52(23):e143–e263.

[2] Moons P, Bovijn L, Budts W, Belmans A, Gewillig M. Temporal trends in survival into adulthood among patients born with congenital heart disease from 1970 to 1992 in Belgium. *Circulation*. 2010;122(22):2264–2272.

[3] Foster E, Graham TP, Driscoll DJ, et al. Task force 2: special health care needs of adults with congenital heart disease. *J Am Coll Cardiol*. 2001;37(5):1176–1183.

[4] A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002;110(6 Pt 2):1304–1306.

[5] Sable C, Foster E, Uzark K, et al. Best practices in managing transition to adulthood for adolescents with congenital heart disease: the transition process and medical and psychosocial issues: a scientific statement from the American Heart Association. *Circulation*. 2011;123(13):1454–1485.

[6] Reid GJ, Irvine MJ, McCrindle BW, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics*. 2004;113(3 Pt 1):e197–e205.

[7] Wacker A, Kaemmerer H, Hollweck R, et al. Outcome of operated and unoperated adults with congenital cardiac disease lost to follow-up for more than five years. *Am J Cardiol*. 2005;95(6):776–779.

[8] Yeung E, Kay J, Roosevelt GE, Brandon M, Yetman AT. Lapse of care as a predictor for morbidity in adults with congenital heart disease. *Int J Cardiol*. 2008;125(1):62–65.

[9] Mackie AS, Ionescu-Ittu R, Therrien J, Pilote L, Abrahamowicz M, Marelli AJ. Children and adults with congenital heart disease lost to follow-up: who and when? *Circulation*. 2009;120(4):302–309.

[10] Goossens E, Stephani I, Hilderson D, et al. Transfer of adolescents with congenital heart disease from pediatric cardiology to adult health care: an analysis of transfer destinations. *J Am Coll Cardiol*. 2011;57(23):2368–2374.

[11] Gurvitz M, Valente AM, Broberg C, et al. Prevalence and predictors of gaps in care among adult congenital heart disease patients. Alliance for Adult Research in Congenital Cardiology (AARCC) and Adult Congenital Heart Association. *J Am Coll Cardiol*. 2013;61(21):2180–2184.

[12] Bohun CM, Woods P, Winter C, et al. Challenges of intra-institutional transfer of care from paediatric to adult congenital cardiology: the need for retention as well as transition. *Cardiol Young*. 2016;26(02):2):327–33.

[13] Gurvitz MZ, Inkelas M, Lee M, Stout K, Escarce J, Chang RK. Changes in hospitalization patterns among patients with congenital heart disease during the transition from adolescence to adulthood. *J Am Coll Cardiol*. 2007;49(8):875–882.

[14] Agarwal S, Sud K, Khera S, et al. Trends in the burden of adult congenital heart disease in US Emergency Departments. *Clin Cardiol*. 2016;39(7):391–398.

[15] Mylotte D, Pilote L, Ionescu-Ittu R, et al. Specialized adult congenital heart disease care. The impact of policy on mortality. *Circulation*. 2014;129(18):1804–1812.

[16] Fernandes S, Khairy P, Fishman L, et al. Referral patterns and perceived barriers to adult congenital heart disease care: results of a survey of U.S. pediatric cardiologists. *J Am Coll Cardiol*. 2012;60(23):2411–2418.

[17] Opotowsky AR, Siddiqi OK, Webb GD. Trends in hospitalizations for adults with congenital heart disease in the U.S. *J Am Coll Cardiol*. 2009;54(5):460–467.

[18] Agarwal S, Sud K, Menon V. Nationwide hospitalization trends in adult congenital heart disease across 2003–2012. *J Am Heart Assoc*. 2016;5(1).

[19] Lu Y, Agrawal G, Lin CW, Williams RG. Inpatient admissions and costs of congenital heart disease from adolescence to young adulthood. *Am Heart J*. 2014;168(6):948–955.

[20] Fernandes SM, Pearson DD, Rzeszut A, Mitchell SJ, Landzberg MJ, Martin GR. Adult congenital heart disease incidence and consultation: a survey of general adult cardiologists. *J Am Coll Cardiol*. 2013; 61(12):1303–1304.

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