

# Functional classification of heart failure before and after implementing a healthcare transition program for youth and young adults transferring from a pediatric to an adult congenital heart disease clinics

Albert C. Hergenroeder MD<sup>1</sup>  | Douglas S. Moodie MD<sup>2</sup> | Daniel J. Penny MD<sup>2</sup>  |  
Constance M. Wiemann PhD<sup>1</sup> | Blanca Sanchez-Fournier BA<sup>1</sup> |  
Lauren K. Moore RN<sup>2</sup> | Jane Head RN<sup>3</sup>

<sup>1</sup>Section of Adolescent Medicine and Sports Medicine, Department of Pediatrics, Baylor College of Medicine, Texas Children's Hospital, Houston, Texas, USA

<sup>2</sup>Section of Cardiology, Department of Pediatrics, Baylor College of Medicine, Texas Children's Hospital, Houston, Texas, USA

<sup>3</sup>Section of Physical Medicine and Rehabilitation, Department of Pediatrics, Baylor College of Medicine, Texas Children's Hospital, Houston, Texas, USA

## Correspondence

Albert C. Hergenroeder, Baylor College of Medicine, Texas Children's Hospital, 6701 Fannin Street, Suite 1710, Houston, TX 77030.  
Email: alberth@bcm.edu

## Funding information

Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Care Needs, Grant/Award number: D70MC23045 and Office of Title V & Family Health, Texas Department of Health and Human Services, using Title V Maternal and Health Services Block Grant Funds, Grant/Award number: 2014004647/0009819A

## Abstract

**Objective:** To describe changes in functional status between the last pediatric and first adult congenital heart disease (CHD) clinic visits in patients with moderate to severe CHD after implementing a healthcare transition (HCT) planning program.

**Design:** Quasi-experimental design. Patients were followed prospectively following the implementation of the intervention; Control patients transitioned from the Pediatric CHD Clinic into Adult CHD Clinic before the intervention.

**Setting:** Texas Children's Hospital (TCH).

**Patients:** Sixteen to 25-year-olds, cognitively normal, English speaking patients with moderate to severe CHD who transitioned from the Pediatric to the Adult CHD clinic.

**Interventions:** An EMR-based transition planning tool (TPT) was introduced into the Pediatric CHD Clinic. Two nurses used the TPT with eligible patients. Independent of the intervention, two medicine-pediatric CHD physicians and one nurse practitioner were added to the ACHD Clinic to address growing capacity needs.

**Outcome Measures:** The New York Heart Association Functional Classification of Heart Failure (NYHA/AFS).

**Results:** Control patients waited  $26 \pm 19.2$  months after their last pediatric clinic visit for their first adult visit. Intervention patients waited  $13 \pm 8.3$  months ( $P = .019$ ). Control and Intervention patients experienced a lapse in care greater than two (50% vs 13%,  $P = .017$ ) and three (30% vs 0%,  $P = .011$ ) years, respectively. The difference between the recommended number of months for follow-up and the first adult appointment ( $15.1 \pm 17.3$  Control and  $4.4 \pm 6.1$  Intervention months) was significant ( $P = .025$ ). NYHA/AFS deteriorated between the last Pediatric visit and the first ACHD visit for seven (23%) Control patients and no Intervention patients ( $P = .042$ ). Four of seven Control patients whose NYHA/AFS declined had a lapse of care of more than two years.

Authors have all contributed to all aspects of the study design, implementation, analyses and review of this document.

**Conclusions:** There is a need for improved HCT planning for patients with moderate to severe CHD, otherwise, lapses of care and adverse outcomes can ensue.

**KEYWORDS**

chronic illness, adolescent and young adults, healthcare transition, forgone care

## 1 | BACKGROUND

Adolescents and young adults with congenital heart disease (AYACHD) constitute a growing population for whom life expectancy has significantly increased in recent decades so that by 2007, there were more adults with CHD than children.<sup>1</sup> Yet success in improving lifespan has not been matched by methods to facilitate a well-planned and executed healthcare transition (HCT) process, which all patients with moderate to severe CHD require.<sup>2</sup> Existing HCT methods for AYACHD are inadequate, contributing to increased morbidity and mortality during the transition from pediatric-based care.<sup>3-5</sup> In a group of adolescents and young adults with moderate to complex CHD, lapses in care of  $\geq 2$  years between the last pediatric and the first adult CHD visit occurred in 63% of patients and 60% of these patients received a new, hemodynamically significant diagnosis at the time of their first adult CHD clinic visit.<sup>6</sup> In addition, combining the absence of effective HCT methods with a dearth of adult cardiologists willing to take young adults with moderate to severe CHD into their practice, some pediatric cardiologists choose to follow patients well into adulthood. More than 50% of pediatric cardiologists care for at least 20 patients  $\geq 21$  years of age and 22%, 13% and 10% cared for at least 20 patients  $> 30$ ,  $> 40$ , and  $> 50$  years of age, respectively.<sup>7</sup> This creates a challenge for providing interdisciplinary care for CHD adults with comorbidities in pediatric hospitals. Six percent of admissions to pediatric hospitals are for adult patients accounting for \$1 billion in charges in the United States, in 1999 dollars.<sup>8</sup>

Given the increased morbidity associated with lapse of care in young adults with moderate to severe CHD during their transition to adult care, the absence of evidence-based HCT methods for patients with CHD, and the lack of published reports examining outcomes of formal HCT programs, the purpose of this study was to describe changes in functional status between last pediatric and first adult CHD clinic visits in patients with moderate to severe CHD after implementing a HCT transition planning program.

## 2 | METHODS

### 2.1 | Needs assessment

A 2011 needs assessment of the HCT processes occurring in the Texas Children's Hospital (TCH) Pediatric Cardiology Clinic demonstrated that there was no formal or written HCT policy. There were two medicine-pediatrics trained pediatric cardiologists to whom patients with CHD could be transferred within the TCH Heart Center and there were no agreed upon criteria for transition readiness. Typically patients who

transitioned to the TCH Adult Congenital Health Disease (ACHD) Clinic were young adults who either had medical issues that the pediatric cardiologist was uncomfortable treating (e.g., pregnancy) or the patient's pediatric cardiologist was retiring. To transition patients, the pediatric cardiologist contacted a provider in the TCH ACHD Clinic by telephone, email, or phone. The TCH Pediatric CHD and ACHD Clinics are in the same building, and they use the same electronic medical record (EMR). The pediatric cardiologist could initiate follow-up on the patient's status at transfer, however there was no formal feedback process.

### 2.2 | Transition planning program

A HCT planning program that emphasized preparing youth for transition to adult-based care was implemented by the TCH Cardiology Service and included: an EMR-based transition planning tool (TPT), developed by one of the authors that was introduced into the TCH Pediatric CHD Clinic in December 2011 to provide a method for HCT planning for patients transitioning to adult-based care. Two research nurses were assigned to use the TPT with all eligible patients. In addition to completion of EMR documentation of TPT administration, the nurses assisted the patients in navigating their transition by providing cardiologist-approved verbal education and written materials about diagnoses and medications; empowering them to speak up if they wanted time without the parent present while talking to their physician, or if they had medical questions; reviewing how to order medication refills from a pharmacy; demonstrating how to enter the in case of emergency (ICE) phone number to their cell phone; providing phone numbers and appointment scheduling instructions for the ACHD Clinic and their other current providers; facilitating a referral from the pediatric cardiology to ACHD clinic with approval from each respective cardiologist; showing them how to look up in-network physicians and contact information on their insurance payer website; and explaining the information contained on their insurance card such as their member identification number and the phone number to call for questions or to speak to a nurse case manager.

Finally, during the study period, two additional medicine-pediatric CHD physicians and one nurse practitioner were added to the TCH ACHD Clinic.

### 2.3 | Study design

A quasi-experimental design was used, with one group of patients followed prospectively as they transitioned to adult care (Intervention patients) following the implementation of the HCT planning program

**TABLE 1** Eligible diagnoses for study inclusion

Common ventricle
Conduits, valved or nonvalved
Crisscross heart
Cyanotic congenital heart
Double-inlet ventricle
Double-outlet ventricle
Eisenmenger syndrome
Fontan procedure or s/p Fontan
Heart transplant or s/p heart transplant
Heterotaxy syndrome
Hypoplastic left heart
Isomerism
Mitral atresia
Primitive ventricle
Pulmonary atresia
Pulmonary vascular obstructive disease (PVOD)
RV to PA conduit
Single ventricle
Transposition of the great arteries
Tricuspid atresia
Truncus arteriosus/hemitruncus
Univentricular heart transposition of great vessels
Ventricular inversion

and the other group of patients identified through the review of medical records as having transitioned out of TCH Pediatric CHD Clinic into adult care before the introduction of the transition planning program (Control patients). Both sets of patients returned to TCH for their ACHD care. Patients who transitioned to other adult providers were not included in the study. The study was approved by the Baylor College of Medicine Institutional Review Board.

## 2.4 | Study subjects

Patients in both groups had moderate to severe CHD (see Table 1 for eligible diagnoses), were English speaking and cognitively normal. Intervention patients ( $n = 25$ ) were 16–25 years of age with a planned transition from the Pediatric CHD Clinic to the TCH ACHD Clinic within 18 months of the start of the intervention (February 2012). To date, 15 patients in the Intervention group have transitioned to the TCH ACHD Clinic. Control patients ( $n = 30$ ) were 18 years of age or older with moderate to severe CHD who had transferred out of the Pediatric CHD Clinic to the TCH ACHD Clinic between 2002 and 2011.

## 2.5 | Measures

Intervention and Control group patient medical records were reviewed for patient age and dates of last pediatric and first adult clinic appointments and recommended length of time to follow-up in the adult clinic. Functional classification of heart failure status was determined by using the New York Heart Association Functional Classification of Heart Failure.<sup>9</sup> Functional classes were evaluated by one of the authors, a pediatric cardiologist, by reviewing their last TCH Pediatric Cardiology clinic visit and first TCH Adult CHD Clinic visit notes with a possible range of I (least severe) to IV (most severe).

## 2.6 | Data analysis

Intervention and Control Group patients were compared on demographic and clinical characteristics and outcomes using Chi-square, Students' *t* or Mann-Whitney U tests, depending on the level of measurement and the extent to which parametric assumptions were met. Since all seven patients whose functional status deteriorated between their last pediatric and adult clinic visit were in the Control group, it was not possible to conduct a logistic regression analysis to examine the independent relationship between group status and functional status change. Multiple linear regression was therefore used to evaluate the association between membership in the Intervention or Control groups and number of months between the last pediatric and first adult clinic visits, a measure reflecting gap in medical care, while controlling for other variables.

## 3 | RESULTS

At their last pediatric visit, Intervention patients were on average almost two years younger than Control patients ( $P = .001$ ; Table 2) and more likely to be classified as functional status II ( $P = .002$ ). By their first adult cardiology appointment, Intervention patients were nearly three years younger than Control patients ( $P < .001$ ; Table 3).

On average, Control patients waited  $26 \pm 19.2$  months following their last pediatric clinic visit to visit the adult clinic (Fig. 1). In contrast, Intervention patients attended their first adult appointment  $13 \pm 8.3$  months after their last pediatric appointment ( $P = .019$ ). Control patients were significantly more likely than Intervention patients to experience a lapse in care of greater than two (15/30, 50% vs 2/15,

**TABLE 2** Group characteristics at last pediatric visit

	Control patients ( $n = 30$ ) N (%)	Intervention patients ( $n = 15$ ) N (%)	P value
Gender, % male	14 (47%)	8 (53%)	NS
Age, mean $\pm$ S.D.	20.3 $\pm$ 1.6	18.5 $\pm$ 1.2	.001
NYHAFS			.002
I	24 (80%)	5 (33%)	
II	6 (20%)	10 (67%)	

Abbreviation: NYHAFS, New York Heart Association Functional Classification of Heart Failure.

TABLE 3 Outcomes at first adult visit

	Control patients (n = 30) N (%)	Intervention patients (n = 15) N (%)	P value
Age, mean $\pm$ S.D.	22.4 $\pm$ 1.6	19.6 $\pm$ 1.5	< .001
NYHAFS			NS
I	19 (63%)	7 (47%)	
II	10 (33%)	8 (53%)	
III	1 (3%)	0	
Change in NYHAFS			.042
Same/improved	23 (77%)	15 (100%)	
Deteriorated	7 (23%)	0	

Abbreviation: NYHAFS, New York Heart Association Functional Classification of Heart Failure.

13%,  $P = .017$ ) and three (10/30, 30% vs 0/15, 0%,  $P = .011$ ) years, respectively. Although the recommended length of time to see an adult provider after leaving pediatric care did not differ statistically between groups (10.7  $\pm$  6.05 vs 8.7  $\pm$  5.09 months for Control and Intervention patients, respectively,  $P = .284$ ), the difference between the recommended number of months for the follow-up appointment and the actual first adult appointment (15.1  $\pm$  17.3 and 4.4  $\pm$  6.1 months delay, respectively) was significant ( $P = .025$ ) with Control patients experiencing a gap over three times the size of Intervention patients.

There was a deterioration in NYHAFS between the last TCH Pediatric CHD Clinic visit and the first TCH ACHD clinic visit for seven (23%) of the Control patients, while none of the Intervention patients deteriorated across that transition ( $P = .042$ ; Table 3). Four of the seven Control patients whose NYHAFS status declined had a lapse of care between the last pediatric and first TCH ACHD clinic of more than two years.

As none of the Intervention patients experienced a deterioration in their NYHAFS between the last TCH Pediatric CHD Clinic visit and the first TCH ACHD clinic visits, it was not possible to conduct a logistic regression predicting this outcome. Multiple linear regression was therefore conducted to examine the independent association between group status (Intervention versus Control) and months between last pediatric and first adult visit. After controlling for age and NYHAFS at

last pediatric visit and number of months recommended by their pediatric cardiologist to follow up with the adult cardiologist, Intervention patients demonstrated a significantly shorter duration between health care visits than Control patients ( $P = .005$ ; Table 4).

## 4 | DISCUSSION

This is the first published study of which the authors are aware to report a temporal association between functional classification of CHF stability in a group of patients with moderate to severe CHD who were transitioned from pediatric to adult-based CHD care following the introduction of a HCT planning program, compared to a historic control group that received no formal HCT planning prior to transition. As reported in a prior publication, the HCT planning program used in this study increased provider awareness of the need for a deliberate HCT planning process,<sup>10</sup> and with increased emphasis on transition, the capacity in the ACHD Clinic was increased. It is likely that enhanced awareness of the need for transition planning, coupled with additional adult capacity, helped reduce the number of months between the last pediatric and first adult CHD Clinic visits. This is important, as lapses of care after leaving pediatric CHD clinics in transition to ACHD clinics have been associated with increased morbidity.<sup>6</sup> In addition, the nurses who implemented the transition planning tool designed to improve transition preparedness also helped the patients navigate the transition to the ACHD Clinic. The use of transition navigators decreased the dropout rate for young adults with diabetes after transition from pediatric to adult care compared to a group of young adult diabetes patients who did not have access to the navigator.<sup>11</sup>

The average lapse in care observed in the historical Control group of 26 months (50% were > 24 months) in this study is consistent with Yeung's<sup>6</sup> study, wherein 63% of patients previously followed by a pediatric cardiologist experienced a lapse in care of greater than two years. In the Yeung study, patients with lapse in care had 3.1x the risk of urgent intervention at the time of their first ACHD clinic visit. In a systematic review of outcomes after transition from pediatric to adult care for young adult CHD patients, lapses in care for > 2 years ranged from 7% to 63%. Similarly, in another study a lapse in care of more than three years was identified in 42% of patients (as compared with 30% for the Control patients in our study) with 8% having gaps more than 10 years.<sup>12</sup> Although we did not determine reasons for lapse in care in our study, Gurvits identified several common reasons, including the patient was feeling well which would apply to the Control group of which 80% had NYHAFS Grade I at the last Pediatric CHD Clinic visit and may have felt well compared to the Intervention group patients of which 67% had NYHAFS Grade II at the last Pediatric CHD Clinic visit. In addition patients with CHD have reported being unaware of the follow-up required, or they had complete absence from all medical care.<sup>12</sup> As further evidence of being unaware of the natural history of their illness, AYACHD with moderate to severe disease have been reported to expect to live as long as their non-CHD peers, yet lack knowledge of the risks associated with their specific CHD.<sup>13</sup> These explanations may apply to the patients in this study but we did not

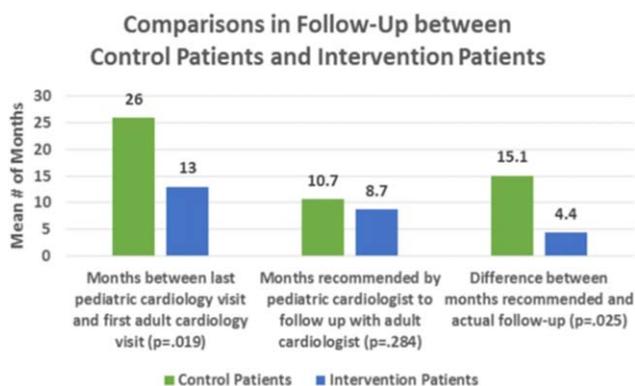


FIGURE 1 Comparisons in follow-up between Control patients and Intervention patients

TABLE 4 Linear regression predicting months between pediatric and adult visits (n = 45)

	B	$\beta$	t	P < value
NYHA/AFS at last pediatric visit	5.099	.155	1.053	.299
Age at last pediatric visit	-2.391	-.256	-1.749	.088
Number of months recommended by pediatric cardiologist to follow up with adult cardiologist	1.217	.441	3.253	.002
Patient group (CP vs IP)	-15.887	-.475	-2.969	.005

Abbreviations: NYHA/AFS, New York Heart Association Functional Classification of Heart Failure; CP, control patients; IP, intervention patients.  $F(4,40) = 6.225$ ,  $P = .001$ ;  $F_{\text{change}}(1,40) = 8.813$ ,  $P = .005$ .

assess for the patient awareness of the severity of their disease or their perceived need to follow-up.

Of the pediatric CHD programs that transferred patients to an adult program, one-third had a formal transition program.<sup>14</sup> Only 7% used a formal transition tool such as a survey, checklist or questionnaire.<sup>7</sup> In contrast, we had a dedicated formal transition process that used a tool. Pediatric cardiologists have indicated that adult comorbidities, pregnancy, age and parental or patient requests were common reasons for transfer.<sup>7,15</sup> Safe care was an issue on the pediatric and adult sides of HCT: some expressed concern about adults being seen on the pediatric side and others expressed concern for lack of expertise in CHD in the adult facilities. In our study, two medicine-pediatric trained CHD physicians and one nurse practitioner were added to the TCH ACHD clinic, eliminating the concern about access to adult providers with expertise in CHD.

## 5 | LIMITATIONS

The patients described here are those who transitioned to the TCH ACHD Clinic; AYACHD patients who left the TCH Pediatric Cardiology Clinic and transitioned to other Adult CHD or adult cardiology clinics were not included. In addition, the Control and Intervention groups may have differed on important variables not measured in this study.

## 6 | CONCLUSIONS

There is a need for improved HCT planning for patients with moderate to severe CHD and this may result in a reduced lapse of care, and potentially, adverse outcomes. Developing a transition planning program emphasizes the importance of earlier transition planning and shorter duration of follow-up in the ACHD clinic. Without a transition planning structure, follow-up is left up to the patients and their families with little guidance, resulting in delays in engaging in adult care and subsequent increased morbidity.

## ACKNOWLEDGMENTS

Cardiology team: Wayne Franklin, Rachel Dugan, Tunu Magwe, Melissa Karlsen, Carol Looney.

## ORCID

Albert C. Hergenroeder MD  <http://orcid.org/0000-0002-2740-596X>

Daniel J. Penny MD  <http://orcid.org/0000-0002-8426-0381>

## REFERENCES

- [1] Marelli AJ, Mackie AS, Ionescu-Iltu R, Rahme E, Pilote L. Congenital heart disease in the general population: changing prevalence and age distribution. *Circulation*. 2007;115(2):163-172.
- [2] 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.
- [3] Bloom SR, Kuhlthau K, Van Cleave J, Knapp AA, Newacheck P, Perrin JM. Health care transition for youth with special health care needs. *J Adolesc Health*. 2012;51(3):213-219.
- [4] Quinn CT, Rogers ZR, McCavit TL, Buchanan GR. Improved survival of children and adolescents with sickle cell disease. *Blood*. 2010;115(17):3447-3452.
- [5] Williams RG. Transitioning youth with congenital heart disease from pediatric to adult health care. *J Pediatr*. 2015;166(1):15-19.
- [6] 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.
- [7] Fernandes SM, 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.
- [8] Okumura MJ, Campbell AD, Nasr SZ, Davis MM. Inpatient health care use among adult survivors of chronic childhood illnesses in the United States. *Arch Pediatr Adolesc Med*. 2006;160(10):1054-1060.
- [9] The Criteria Committee of the New York Heart Association. Nomenclature and Criteria for Diagnosis of Diseases of the Heart and Great Vessels. 9th ed. Boston, MA: Little, Brown & Co; 1994.
- [10] Wiemann CM, Hergenroeder AC, Bartley KA, et al. Integrating an EMR-based transition planning tool for CYSHCN at a children's hospital: a quality improvement project to increase provider use and satisfaction. *J Pediatr Nursing*. 2015;30(5):776-787.
- [11] Van Wallegem N, Macdonald CA, Dean HJ. Evaluation of a systems navigator model for transition from pediatric to adult care for young adults with type 1 diabetes. *Diabetes Care*. 2008;31(8):1529-1530.
- [12] Gurvitz M, Valente AM, Broberg C, et al. Prevalence and predictors of gaps in care among adult congenital heart disease patients:

- HEART-ACHD (The Health, Education, and Access Research Trial). *J Am Col Cardiol*. 2013;61(21):2180–2184.
- [13] 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.
- [14] Heery E, Sheehan AM, While AE, Coyne I. Experiences and outcomes of transition from pediatric to adult health care services for young people with congenital heart disease: a systematic review. *Congenit Heart Dis*. 2015;10(5):413–427.
- [15] Hilderson D, Saidi AS, Van Deyk K, et al. Attitude toward and current practice of transfer and transition of adolescents with congenital heart disease in the United States of America and Europe. *Pediatr Cardiol*. 2009;30(6):786–793.

**How to cite this article:** Hergenroeder AC, Moodie DS, Penny DJ, et al. Functional classification of heart failure before and after implementing a healthcare transition program for youth and young adults transferring from a pediatric to an adult congenital heart disease clinics. *Congenital Heart Disease*. 2018;13:548–553. <https://doi.org/10.1111/chd.12604>