Cardiology in the Young

cambridge.org/cty

Transition of care in CHD: a single-centre experience: an enigma remains

Christine Lopez[1], Brittany Glassberg[1], Alexandra Dembar[1], Maria Riasat[2], Alice Chan[3], Usha Govindarajulu[4], Kali A. Hopkins[3] and Ali N. Zaidi[3,5]

[1]Icahn School of Medicine at Mount Sinai, New York, NY, USA; [2]Department of Medicine, Mount Sinai Beth Israel, New York, NY, USA; [3]Mount Sinai Adult Congenital Heart Disease Center, Mount Sinai Heart, New York, NY, USA; [4]Center for Biostatistics, Department of Population Health Science and Policy, Icahn School of Medicine at Mount Sinai, New York, NY, USA and [5]Mount Sinai Children's Heart Center, Kravis Children's Hospital, New York, NY, USA

Original Article

Cite this article: Lopez C, Glassberg B, Dembar A, Riasat M, Chan A, Govindarajulu U, Hopkins KA, and Zaidi AN (2024) Transition of care in CHD: a single-centre experience: an enigma remains. *Cardiology in the Young* **34**: 727–733. doi: 10.1017/S1047951123002548

Received: 27 November 2022
Revised: 20 April 2023
Accepted: 15 June 2023
First published online: 29 September 2023

Keywords:
Transition of care; CHD; loss to follow-up

Corresponding author:
Ali N. Zaidi; Email: ali.zaidi@mountsinai.org

Abstract

Transition of care refers to the continuity of health care during the movement from one healthcare setting to another as care needs change during a chronic illness. We sought to describe social, demographic, and clinical factors related to successful transition in a tertiary urban care facility in patients with CHD. Patients were identified utilising the electronic medical record. Inclusion criteria were patients with CHDs aged ≥15 years seen in the paediatric cardiology clinic between 2013 and 2014. Deceased patients were excluded. Clinical and demographic variables were collected. Patient charts were reviewed in 2015–2021 to determine if included patients were a) still in paediatric cardiology care, b) transitioned to adult cardiology/adult CHD, or were c) lost to follow-up. A total of 322 patients, 53% male (N:172), 46% female (N:149) were included. Majority had moderately complex lesions (N:132, 41%). Most patients had public insurance (N:172, 53%), followed by private insurance (N:67, 21%), while 15% of patients (N:47) were uninsured. Only 49% (N = 159) had successful transition, while 22% (N = 70) continued in care with paediatric cardiology, and 29% (N = 93) were lost to follow-up. Severity of CHD ($p = 0.0002$), having healthcare insurance ($p < .0001$), presence of a defibrillator ($p = 0.0028$), and frequency of paediatric cardiology visits ($p = 0.0005$) were significantly associated with successful transition. Most patients lost to follow-up (N:42,62%) were either uninsured or had public insurance. Lack of successful transition is multifactorial, and further efforts are needed to improve the process in patients with CHD.

Introduction

Children born with complex childhood illnesses like CHD are now surviving into adulthood. In fact, the number of adults born with CHD is rising exponentially in the United States, with an estimate that there are now more adults living with CHD than children with CHD.[1–3,4,5] A retrospective review of death certificates found that mortality has been declining from CHD, with a decrease of 24% between 1999 and 2006.[6]The expectation is for these patients to successfully enter adulthood and lead normal and productive lives. However, these patients need to transition their care from paediatric to adult-centred care in a timely fashion for optimal long-term outcomes. Often in the absence of established transition of care programmes, there is delayed, inappropriate, or incomplete transition of care. This often leads to fragmented care as well as emotional and financial stress on patients, their families, and the healthcare system. Lapses in care due to lack of successful transition of care from paediatric to adult care put young adults with CHD at risk for increased morbidity and premature death.[2] Hence, transition and eventual transfer of care from paediatric to adult care is a crucial process to ensure lifelong access to specialised care.[2]

The process of transition of care has been described and endorsed by the American Academy of Paediatrics which states that "the goal of transition in health care for young adults with special healthcare needs is to maximise lifelong functioning and potential through the provision of high-quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood."[7] The American Academy of Paediatrics advises that parents and their doctors begin to plan for transition as early as age 12, and they also advise parents to plan for the move to an adult doctor between ages 14 and 18.[7] However, despite these suggestions, the process of transition of care across several chronic healthcare conditions including CHD remains poorly executed across the United States.

Transition of care refers to the coordination and continuity of health care during movement from one healthcare setting to another and/or between healthcare practitioners as care needs change during a chronic illness.[8] Transition encompasses the process of patient and family education and preparation for young patients to assume their own care as they enter adulthood.[5] It is important to differentiate transition from the process of "Transfer of Care" which refers to a

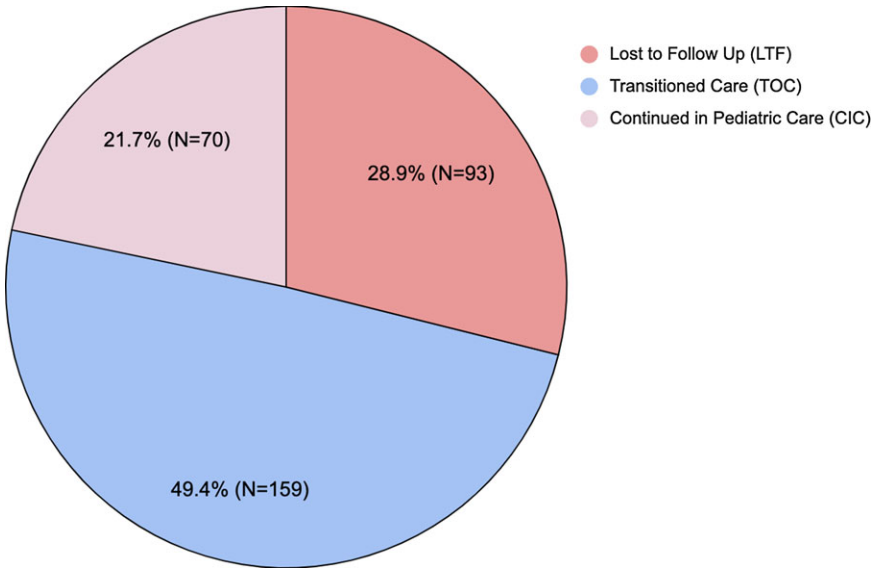

Figure 1. Transition of care: breakdown into LTF, CIC, and TOC. **Abbreviations:** LTF: lost to follow-up, CIC: continued in care, TOC: transition of care.

timepoint when the care of a patient with chronic healthcare conditions is handed off to an appropriate adult care provider. For young patients in their adolescence with chronic illnesses, the focus of transition of care is typically on moving their "medical home" successfully from the paediatric to the adult healthcare setting, which includes bolstering education around the chronic medical condition and emphasising patient independence and autonomy.[9,10] As children mature into young adults, their medical and psychosocial needs evolve beyond the scope of practice of their paediatric doctors, necessitating the process of transition to the adult setting.[8]

It is now well recognised that a significant proportion of patients with CHD are lost to follow-up during a vulnerable period in their lives as they transition from paediatric to adult healthcare settings. This highlights the importance of establishing formal transition programmes. Many barriers have been described that can hinder successful transition without appropriate transfer of care, with high proportions of adolescent patients with CHD experiencing long gaps in care after leaving paediatric cardiology, even among those with severe CHD lesions.[4,11] Most adolescents and adults with moderate and severely complex CHD are at significant risk for long-term complications such as heart failure, arrhythmia, need for additional interventional or surgical procedures, and premature mortality. Notably, patients who receive specialised and non-interrupted comprehensive care often have better outcomes.[12] According to Mylotte et al., there is an independent association between specialised adult CHD care and reduced mortality driven primarily by patients with severe underlying CHD.[13] Therefore, it is imperative to understand the scope of this problem in both urban and non-urban settings. In this study, we sought to describe social, demographic, and clinical factors related to successful transition in a tertiary urban care facility in patients with CHD.

Materials and methods

Patients were identified utilising the electronic medical record (Epic) generated data warehouse. Inclusion criteria were patients with CHDs based on the AHA/ACC Guidelines 2018[14] and age ≥15 years seen in the ambulatory paediatric cardiology clinic between 2013 and 2014. The only exclusion criteria were deceased patients. Clinical and demographic variables were collected by retrospective chart review. Patient charts were reviewed for the years 2015–2021 to determine if patients who met inclusion criteria were a) continued in care with paediatric cardiology, b) transitioned to adult cardiology or adult CHD, or were c) lost to follow-up. Independent predictors for successful transition of care or lost to follow-up were analysed using chi-squared tests. Severity of CHD was determined via the ACC/AHA adult CHD anatomy and physiology classification system per the national guidelines.[14] The frequency of paediatric cardiology visits was stratified into the following: annually, biannually, quarterly, and less than annually. Insurance information for each patient was collected and stratified into uninsured versus insured. The number of comorbidities and medications was collected for each patient.

Patients were sub-stratified into the following three categories: lost to follow-up, CIC whether are with paediatric cardiology, and transition of care to either adult cardiology or adult CHd. Transition to adult care was defined as at least one visit with a member of the adult CHD or an adult cardiology team. Statistical analysis was performed using the Pearson chi-square test of independence for each association. Analysis of variance was used with the numeric variables to describe the averages across the three transition groups. A post hoc two-sided *t*-test of adjusted means was used to determine the statistically significant difference between the groups. The number of comorbidities as well as the number of medications were compared across the three groups separately by using an analysis of variance for each outcome. In addition, adjusted means from each model were compared via post hoc testing.

Results

A total of 322 patients were identified (Fig 1), with 46% (N = 149) being female, 53% (N = 172) being male, and 1 patient identifying as non-binary. The majority of patients had moderate CHD (41%, N = 132). Only 9% (N = 30) had simple CHD while 17% (N = 55) had severely complex CHD (Table 1). The most common defects by complexity were simple CHD lesions: ventricular septal defect (N = 21, 6%), moderate CHD: tetralogy of Fallot (N = 28, 9%) and

https://doi.org/10.1017/S1047951123002548 Published online by Cambridge University Press

Table 1. Baseline demographics

Patient characteristics	Percent (N = 322)
Gender	
Female	149 (46%)
Male	172 (53%)
Non-Binary	1 (1%)
Complexity of CHD*	
Complex	55 (17%)
Moderate	132 (41%)
Simple	30 (9%)
Other	105 (33%)
Insurance status	
Private	67 (21%)
Public	172 (53%)
Uninsured	47 (15%)
Other	11 (3%)
Unknown	25 (8%)

severe CHD: transposition of the great arteries (N = 20, 6%) (Table 2). Of the 322 patients, the majority of patients (53%, N = 172) had public insurance, followed by 67 patients (21%) with private insurance, while 47 patients (15%) were uninsured (Table 1). Regarding transition of care, of the 322 patients, 93 pts (29%) were lost to follow-up, 159 patients (49%) were seen by adult cardiology/adult CHD (successful transition of care) and 70 patients (22%) CIC with paediatric cardiology (Fig 1).

A total of 188 patients were categorised with simple, moderate, or complex CHD lesions based on the AHA/ACC 2018 guidelines (Fig 2). Of the patients who were lost to follow-up, most (N:30, 64%) had moderate lesions followed by simple (N;11, 23%) and complex (N:6, 13%). Of the patients who CIC with paediatric cardiology, most (N:33, 66%) had moderate lesions followed by complex lesions (N:9, 18%), and simple lesions (N:8, 16%). Finally, of patients who successfully transitioned care, the majority had moderate lesions (N:75, 82%), followed by complex (N:10, 11%) and simple lesions (N:6, 7%) (Fig 2).

A chi-square test of independence revealed that the severity of CHD diagnosis was significantly associated with successful transition of care ($\chi^2 = 25.9779$, 6 df, $p = 0.0002$), with more complex lesions leading to a higher rate of successful transition. Having any form of healthcare insurance was associated with successful transition of care ($\chi^2 = 45.6969$, 2 df, $p < .0001$), compared to those patients who were uninsured with a higher loss to follow-up rate. Presence of an implantable cardioverter defibrillator was significantly associated with successful transition of care ($\chi^2 = 11.7605$, 2 df, $p = 0.0028$). In addition, higher frequency of paediatric cardiology visits was significantly associated with successful transition of care ($\chi^2 = 24.3249$, 6 df, $p = .0005$).

The analysis of variance test provided for comorbidities showed a significant difference in average number of comorbidities among the different transition groups ($F = 17.48$, $p < 0.0001$). Post hoc comparisons showed a significant difference between the CIC (with paediatric cardiology) and lost to follow-up groups ($p < 0.001$) with those patients with more comorbidities being in the CIC group. Patients with fewer medical comorbidities were more likely to be lost to follow-up. No significant difference was found in comorbidities between the lost to follow-up and successful transition of care group.

The most prevalent medications in our patient population included aspirin, lisinopril, enalapril, furosemide, and beta-blockers. An analysis of the average number of medications found a significant difference in the number of medications between the transition of care groups ($F = 7.33$, $p = .0008$). Post hoc comparisons showed that pts with a higher number of medications had successful transition of care, when compared to those who CIC ($p = 0.0034$). Similarly, patients who were on fewer medications tended to have a higher rate of lost to follow-up when compared to those who had successful transition of care ($p = 0.0011$). The average number of medications was not significantly different between CIC and lost to follow-up groups ($p = 0.9477$).

Discussion

Despite the growth of adult CHD as a specialised field over the last few decades, many adolescents and young adults with CHD are often lost to follow-up or experience long gaps in care after leaving paediatric cardiology due to lack of appropriate transition of care.[9] The expanding adolescent CHD population in the United States continues to bring new challenges as these patients age into adulthood. This single-centre study at a large urban centre describes the rate and factors associated with transition of care, including lost to follow-up and CIC in adolescents with all forms of CHD. Transition of care is a crucial and critical process to provide access to specialised care and lifelong surveillance. Despite this, there remains a high proportion of young patients with CHD in the United States who are unable to successfully go through transition of care and are lost to follow-up. Most patients with CHD, especially those with moderate and severely complex lesions, will require periodic assessment as they transition into adulthood, owing to the potential need for re-interventions, screening for arrhythmias or congestive heart failure. Many patients as they enter their third and fourth decades of life can also develop non-cardiac comorbidities, including liver, renal, endocrine, and neurological conditions. It is imperative that these patients receive uninterrupted health care which should include the period spanning adolescence to adulthood.

Over the last decade, though several steps have been identified to improve transition, the outcomes for successful transition in CHD continue to be suboptimal. In 2004, Reid et al had reported that only 48% of adolescents with CHD underwent successful transition. Their data suggested that ongoing discussions during adolescence with a focus on the importance of transition was of significant value to successful transition of care.[9] In a 2015 study, fewer than 30% of adults with CHD were appropriately followed by specialised providers, and only 48% of adolescent patients with CHD underwent successful transfer to adult care.[15] A multi-country systematic review from 2021 found that "discontinuity of care" had a pooled estimate proportion of 26.1% among the 17 studies included and the proportions were significantly higher in studies from the United States and in patients with simple CHD lesions.[16] In 2022, Moore et al described that 33% of their cohort were "actively missing" from care meaning they had not engaged in cardiac care and when the study engaged these patients, only 3% of them successfully returned to care.[17] Despite ongoing efforts, the trends regarding transition of care have not significantly changed over time, necessitating the ongoing importance of determining

https://doi.org/10.1017/S1047951123002548 Published online by Cambridge University Press

Table 2. CHD lesions by complexity

Simple	CHD diagnosis	Total
	Patent ductus arteriosus	8 (3%)
	Ventricular septal defect	21 (6%)
	Atrial septal defect	1 (0.3%)
Total		**30 (9%)**
Moderate	CHD diagnosis	N
	Tetralogy of Fallot	28 (9%)
	Sub-pulmonary stenosis	2 (0.6%)
	Subaortic stenosis	6 (2%)
	Bicuspid aortic valve with aortic stenosis/regurgitation	14 (4%)
	Moderate or large atrial septal defects	19 (6%)
	Pulmonary stenosis with RV-PA conduit	1 (0.3%)
	Large ventricular septal defect	2 (0.6%)
	Partial anomalous pulmonary venous connection	3 (0.9%)
	Congenital mitral valve disorder	6 (2%)
	Ebstein anomaly	4 (1.2%)
	Coronary artery aneurysm/anomaly/ fistula	10 (3%)
	AV canal defect	10 (3%)
	Coarctation of the aorta	19 (6%)
	Congenital aortic stenosis/regurgitation	8 (2.4%)
Total		**132 (41%)**
Complex	CHD diagnosis	N
	Truncus arteriosus	2 (0.6%)
	Tricuspid atresia S/P Fontan palliation	4 (1.2%)
	Transposition of the great arteries	20 (6.2%)
	Total anomalous pulmonary venous return	9 (2.8%)
	Pulmonary atresia S/P Fontan palliation	2 (0.6%)
	Hypoplastic left heart syndrome S/P Fontan palliation	7 (2%)
	Double outlet right ventricle	5 (1.5%)
	Double-chambered right ventricle	3 (0.9%)
	Double inlet left ventricle S/P Fontan palliation	3 (0.9%)
Total		**55 (17%)**
Other		**105 (33%)**
Total		**322**

underlying factors that prevent engagement in health care for this high-risk population.

Several barriers to successful transition have been described in the literature. In the United States of America healthcare system, healthcare insurance has proven to be a barrier to successful transition, since patients with CHD may lose access to their parents' insurance as they get closer to the actual age of transfer of care.[5] On an individual level, there is often reluctance from the patient, the patient's family, and the patient's paediatric cardiologist due to a perceived lack of quality adult CHD providers, emotional/ cognitive delay of an adolescent patient with CHD, and a lack of structured transition programmes. Furthermore, transition is often avoided due to a patient's and parental's anxiety about the transition process and misperceptions about a patient's prognosis and long-term consequences of their actions.[4] It has also been shown that adolescents with CHD are unconcerned about transition, lack knowledge about their underlying cardiac condition and are inadequately prepared for transfer to the adult healthcare setting. Many adolescents desire continuity in the paediatric setting with youth-oriented facilities, a personalised approach, and prefer that their parents remain involved in their care, but only in a secondary, supportive capacity.[15] Moceri et al revealed loss to follow-up may be due to poor health literacy and inadequate discussion highlighting the importance of the transition process.[9,18]

Factors that have been shown to protect against a lapse in care include the following: beliefs that specialised adult care was necessary; poorer health status; attendance at paediatric appointments without parents; and direct paediatric referral to an adult CHd centre or programme.[19,20]

There has been a wide variation in reported percentages of patients with CHD who had lapses in care or were lost to follow-up. However, several of these studies are limited by being small cohorts of patients with variable study populations and recruitment methods. Within our single centre, 93 of 322 patients (28.9%) were lost to follow-up which is similar to several prior studies.[21] The growing adult CHd population remains heterogeneous, ranging from those with mild defects requiring little or no intervention to moderate and severely complex CHD lesions. The distribution of CHD severity in our population is similar to previously published estimates.[3,21,22]

Our data suggest that the severity of CHD diagnosis was significantly associated with successful transition of care, with more complex lesions leading to a higher rate of successful transition. This is similar to prior studies.[23,24] However, it does suggest that patients with simple CHD lesions were more likely to be lost to follow-up. It is postulated, though not studied, that patients with simple CHD may be more prone to lost to follow-up since their understanding is that they do not need long-term follow-up and thus do not pursue transition of care.

Though the process of transition has been described in the literature over the last few decades, successful implementation of a transition process requires purposeful movement of adolescents and young adults from child-centred to adult-oriented healthcare systems. This is integral to minimise morbidity and mortality; however, most CHD programmes still do not have formal transition programmes. Though our centre has adjoining adult and paediatric cardiology programmes within the same health system, there was no formal transition of care programme at the time of this study. This allowed significant variability in the transition process based on patient, family, and paediatric cardiac provider's preferences as to how patients should continue their long-term care, resulting in nearly 29% of CHD patients being lost to follow-up. These patients should have benefited from long-term continuity of care but instead were lost to follow-up. This represents a significant portion of patients with suboptimal transition and is consistent with prior studies that report that nearly half of adult CHD patients experience significant gaps in cardiology care at some point in their lives.[10,25] Our study also demonstrated that almost 22% (N = 70) of the patients CIC with paediatric cardiology, thus continuing to receive

https://doi.org/10.1017/S1047951123002548 Published online by Cambridge University Press

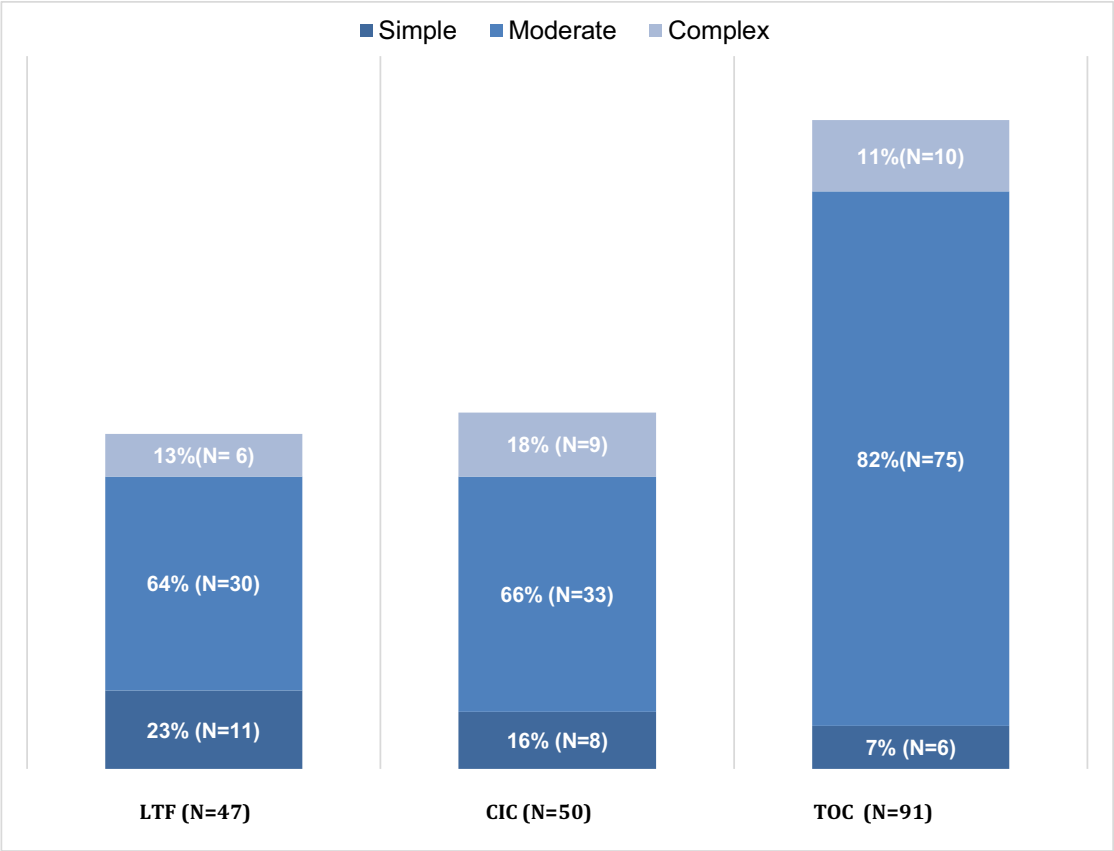

Figure 2. Transition of care by CHD severity. **Abbreviations:** LTF: lost to follow-up, CIC: continued in care, TOC: transition of care.

long-term care and were not lost to follow-up. Being positioned at a large urban care setting with both departments residing in the same healthcare system, we would have expected more patients to have successful transition, however only 49% of patients (N = 159) had successful transition of care. For the purposes of this study, successful transition was considered contact with an adult CHd or a general adult cardiologist.

Many patients with CHD may lose access to their parents' insurance as they get closer to the actual age of transfer of care.[5] The Patient Protection and Affordable Care act, signed into law in 2010, ensured medical coverage for patients with pre-existing conditions and allowed young adults to remain on their parent's insurance policy until age 26 years. However, despite widespread availability and access to health insurance, barriers to accessing high-quality adult cardiac care still exist and often patients are unable to procure healthcare insurance leading to loss of follow-up. Of the 322 patients, the majority of the patients (77%, N = 250) had some form of healthcare insurance, while 47 pts (15%) were uninsured. When stratified into insured and uninsured, having any form of healthcare insurance was associated with successful transition, suggesting that a lapse in healthcare insurance coverage was a predisposing factor to experiencing a gap in care.

Our study also showed that those patients taking multiple medications had improved chances of long-term continuity of care which has also been reported in prior studies.[21] Similarly, it has been reported that patients who had undergone particular cardiac interventions, such as an implantable defibrillator, were more likely to remain in care thus leading to successful transition. These findings suggest that patients with CHD seem to stay in care when they are on medications or have cardiac devices or interventions, since they need to have these medications refilled or have their cardiac devices followed over a longer period of time, thus preventing a gap in follow-up care.

Limitations

Limitations include the retrospective analysis of data and inability to assess continuity of care outside our healthcare system in those who could not be contacted. The collected and analysed data was extracted from an electronic medical record and is subject to coding variations of CHD lesions. In addition, our study did not include analysis of patient or family understanding of the need for lifelong care for patients with CHD, their impressions of transitioning to adult cardiology, or the effect of cognitive impairment on the rate of successful transition. Lastly, our study did not investigate the different practices of the individual paediatric cardiologists as to when and if they initiate the process of transition.

Conclusions

The process of transition of care is well recognised and endorsed by the American Academy of Pediatrics since 2002.[7] More recently, the American Academy of Pediatrics along with the American Academy of Family Physicians and the American College of Physicians updated their recommendations for transition of care in 2018.[26]

Due to the increasing number of patients with CHD undergoing transition, multiple governing academic bodies have put forth statements regarding the importance of transition of care for the

https://doi.org/10.1017/S1047951123002548 Published online by Cambridge University Press

CHD population. In 2008 and then in 2018, the American College of Cardiology / American Heart Association guideline documents for the management of adult CHd placed significant emphasis on the successful transition of care for patients with CHD.[19,27] In 2011, best practices in managing transition of adolescents with CHD to adulthood was published by the American Heart Association.[8] Unfortunately, despite advances in the field, there continue to be lapses in care which appear to be predictors for morbidity and poor longer outcomes, particularly for minority populations.[13,28] Today, despite over two decades of national efforts, there are still unmet American Academy of Pediatrics needs for this high-risk population. It is now well established that the transition of care process with eventual transfer of care for children with CHD should include a referral or contact with a specialised adult CHd centre.

This single-centre study aimed to explore various factors associated with successful American Academy of Pediatrics or lost to follow-up from paediatric to adult cardiology or adult CHd for adolescents and adults with CHD in a tertiary urban care centre. Successful transition can be empowering for patients and their families, as they build a new therapeutic relationship with an appropriate adult provider.

In our single-centre experience, patients with greater complexity of CHD, those using medications, those with an implantable defibrillator, and those with healthcare insurance were more likely to stay in medical care and undergo successful transition. Patients with simple CHD represent a subgroup with higher rates of lapses in care and who may benefit from increased scrutiny and focused transition education. In the context of the increasing numbers of adult CHd patients in the United States that continues to rise, there is an immediate and urgent need to improve the process of transition in patients with CHD to improve the long-term outcomes and allow these young people to meet their full adult potential in the years to come.

Acknowledgements. None.

Financial support. None.

Competing interests. All authors have no conflict of interest.

Ethical standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation (please name) and with the Helsinki Declaration of 1975, as revised in 2008, and have been approved by the institutional review board at Mount Sinai.

References

1. Gilboa SM, Salemi JL, Nembhard WN, Fixler DE, Correa A. Mortality resulting from congenital heart disease among children and adults in the United States, 1999 to 2006. Circulation 2010; 122: 2254–2263.
2. Marelli AJ, Ionescu-Ittu R, Mackie AS, Guo L, Dendukuri N, Kaouache M. Lifetime prevalence of congenital heart disease in the general population from 2000 to 2010. Circulation 2014; 130: 749–756.
3. Marelli AJ, Mackie AS, Ionescu-Ittu R, Rahme E, Pilote L. Congenital heart disease in the general population: changing prevalence and age distribution. Circulation 2007; 115: 163–172.
4. Lee A, Bailey B, Cullen-Dean G, Aiello S, Morin J, Oechslin E. Transition of care in congenital heart disease: ensuring the proper handoff. Curr Cardiol Rep 2017; 19: 55.
5. Cotts TB. Transition of care in congenital disease: allaying fears for patients and specialists. Prog Cardiovasc Dis 2018; 61: 282–286.
6. Mandalenakis Z, Giang KW, Eriksson P, et al. Survival in children with congenital heart disease: have we reached a peak at 97%? J Am Heart Assoc 2020; 9: e017704.
7. American Academy of P, American Academy of Family P, American College of Physicians-American Society of Internal M. A consensus statement on health care transitions for young adults with special health care needs. Pediatrics 2002; 110: 1304–1306.
8. 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: 1454–1485.
9. 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: e197–205.
10. 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 Coll Cardiol 2013; 61: 2180–2184.
11. 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: 302–309.
12. Nicolarsen J. Transition of adolescents and young adults with congenital heart disease: challenges, progress, and future improvements. Pediatr Ann 2017; 46: e224–e228.
13. Mylotte D, Pilote L, Ionescu-Ittu R, et al. Specialized adult congenital heart disease care: the impact of policy on mortality. Circulation 2014; 129: 1804–1812.
14. Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC guideline for the management of adults with congenital heart disease: executive summary: a report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation 2019; 139: e637–e697.
15. 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: 413–427.
16. Moons P, Skogby S, Bratt EL, Zuhlke L, Marelli A, Goossens E. Discontinuity of cardiac follow-up in young people with congenital heart disease transitioning to adulthood: a systematic review and meta-analysis. J Am Heart Assoc 2021; 10: e019552.
17. Moore JA, Sheth SS, Lam WW, et al. Hope is no plan: uncovering actively missing transition-aged youth with congenital heart disease. Pediatr Cardiol 2022; 43: 1046–1053.
18. Moceri P, Goossens E, Hascoet S, et al. From adolescents to adults with congenital heart disease: the role of transition. Eur J Pediatr 2015; 174: 847–854.
19. Warnes CA, Williams RG, Bashore TM, et al. ACC/AHA 2008 Guidelines for the management of adults with congenital heart disease: executive summary: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (writing committee to develop guidelines for the management of adults with congenital heart disease). Circulation 2008; 118: 2395–2451.
20. Webb GD, Williams RG. Care of the adult with congenital heart disease: introduction. J Am Coll Cardiol 2001; 37: 1166.
21. Kollengode MS, Daniels CJ, Zaidi AN. Loss of follow-up in transition to adult CHD: a single-centre experience. Cardiol Young 2018; 28: 1001–1008.
22. Warnes CA, Liberthson R, Danielson GK, et al. Task force 1: the changing profile of congenital heart disease in adult life. J Am Coll Cardiol 2001; 37: 1170–1175.
23. Norris MD, Webb G, Drotar D, et al. Prevalence and patterns of retention in cardiac care in young adults with congenital heart disease. J Pediatr 2013; 163: 902–4 e1.
24. Valente AM, Lewis M, Vaziri SM, et al. Outcomes of adolescents and adults undergoing primary Fontan procedure. Am J Cardiol 2013; 112: 1938–1942.
25. Knauth A, Verstappen A, Reiss J, Webb GD. Transition and transfer from pediatric to adult care of the young adult with complex congenital heart disease. Cardiol Clin 2006; 24: 619–629, vi.
26. White PH, Cooley WC, Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family

https://doi.org/10.1017/S1047951123002548 Published online by Cambridge University Press

Physicians, American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics 2018; 142: e20182587. DOI: 10.1542/peds.2018-2587. Epub 2018 Oct 22. Erratum in: Pediatrics. 2019 Feb;143(2): PMID: 30348754.

27. Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC guideline for the management of adults with congenital heart disease: a report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation 2019; 139: e698–e800.
28. Lotstein DS, Inkelas M, Hays RD, Halfon N, Brook R. Access to care for youth with special health care needs in the transition to adulthood. J Adolesc Health 2008; 43: 23–29.

https://doi.org/10.1017/S1047951123002548 Published online by Cambridge University Press