

Burger, Debora: Dissertation

**Transition of Pediatric Patient with Congenital Heart Disease to Adult Specialty
Care in the United States**

A Dissertation

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Abstract

Background: Patients with congenital heart disease (CHD) require uninterrupted lifelong specialized cardiac care, yet the transition years are a vulnerable time for these patients. Transition programs offer structured support to patients with CHD with the aim of improving CHD knowledge, independence in care, and providing an uninterrupted transfer process and integration into accredited adult congenital heart disease (ACHD) programs. Transition has three components: preparation, transfer and integration. The main barriers to successful transition program implementation are time and resources to complete transition practices and there is no best model for transition programs. Patients with CHD in the United States (US) have a lower occurrence of transfer to ACHD programs, and they experience more gaps in care during the transition years compared with Canada and Europe. Structured transfer processes to ACHD programs are common in Europe, but these, and overall transition practices in the US are not well understood.

Purpose: The purpose of this dissertation is to test a low resource intervention to facilitate patient preparation, identify factors that improve effective transfer, and evaluate transition practices in the US. Three specific aims were set forth to accomplish this purpose: 1) to test a low resource transition activity for pediatric patients with CHD in the pediatric cardiology ambulatory care setting; 2) quantify differences in time to transfer to ACHD centers between patients with moderate and great complexity CHD who received a referral order versus those who did not; and 3) characterize ACHD transition practices across the US.

Methods: First, we performed a prospective exploratory study of a medical assistant-facilitated transition intervention in the pediatric cardiology clinic. We compared the presence of documentation of transition discussions between the transition activity and a historical control

group. We also tested staff acceptability of this activity. Second, we analyzed data collected from pediatric patients with moderate and great complexity CHD who were eligible to transfer to our tertiary center's accredited ACHD center. We examined transfer outcomes and time-to-transfer between those with a referral order placed at the last pediatric cardiology visit and those without. Third, we conducted a descriptive, cross-sectional survey of ACHD programs in the US to explore transition practices.

Results: The cumulative results from this body of work tested and identified low resource intensive transition practices to aid in patient preparation and transfer and supplied us with a limited understanding of current transition practices at ACHD programs in the US. Specifically, we found that 1) an MA-facilitated transition intervention increased documentation of transition discussions in the pediatric cardiac clinic and staff were accepting of this activity; 2) placement of a referral order led to increased transfer occurrence and decreased time to transfer to ACHD programs; and 3) over two-thirds of respondent ACHD programs reported the presence of formal transition programs, but more support staff are needed within these programs to address transition practices.

Conclusion: This program of research made meaningful contributions to CHD transition research by testing and exploring low resource intensive transition practices and providing a benchmark of transition practices at ACHD programs in the US. These findings indicate that low resource practices may improve long-term transition outcomes (such as patients' readiness for transfer), improve transfer occurrence to ACHD programs, and generate amenable targets for intervention to optimize transition practices.

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CHAPTER I

Introduction

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Background and Significance

Congenital heart disease (CHD) arises from abnormal fetal cardiac development in utero and encompasses a broad range of structural heart abnormalities that range from simple to great complexity (Stout et al., 2019). The prevalence of CHD is around 8.14 per 1000 live births in the United States (US) (Reller et al., 2008). The global prevalence of CHD from 1979 to 2017 was estimated to be 8.2 per 1000 live births (Liu et al., 2019). There are regional discrepancies of CHD prevalence globally with Africa having the lowest prevalence and Asia the highest (Liu et al., 2019). CHD is associated with genetic conditions (Frogoudaki, 2022), socioeconomic factors, environmental risk factors such as exposure to air pollution and toxic chemicals during pregnancy, maternal health such as diseases during pregnancy, diabetes mellitus, obesity and drug intake, parental smoking and artificial reproduction (Lee et al., 2021).

CHD can be classified in different ways. Marelli and colleagues (2007) classified CHD in two categories: 'severe' lesions being those associated with cyanosis or requiring surgery early in life, and 'other' being all remaining lesions (Marelli et al., 2007). The lesions were further categorized into five hierarchical blocks. All 'severe' lesions were categorized into block one, and remaining lesions in blocks two to five (Marelli et al., 2007). Others developed six hierarchical categories, three of which contained 'severe' CHD subtypes (Botto et al., 2007; Liu et al., 2016). The 2018 American Heart Association (AHA)/ American College of Cardiology (ACC) guideline for the management of adults with CHD writing committee developed the ACHD Anatomic and Physiological (AP) classification system which incorporates both anatomic and physiological variables. The AHA/ACC 2018 guidelines define simple CHD anatomy as small and isolated atrial septal defects and ventricular septal defects, mild isolated pulmonic stenosis or repaired conditions without significant shunts or chamber enlargement (Stout et al., 2019). The guideline defines moderate complexity CHD as non-cyanotic defects that are either repaired or unrepaired and moderate in nature such as anomalous pulmonary venous

connection, atrio-ventricular septal defects, coarctation of the aorta, repaired tetralogy of Fallot. Great complexity CHD anatomy is defined as cyanotic defects which are unrepaired or palliated (Stout et al., 2019). The physiology variables included in the classification are New York Heart Association functional classification system, the presence of hemodynamic or anatomic sequelae, the presence of arrhythmias, exercise capacity, and end organ function (Stout et al., 2019). For the purposes of the transition focus of this dissertation our definition will be based on these guidelines.

Historically only 30-40% of CHD patients reached their tenth birthday (Macmahon et al., 1953). As a result of major advances in medical and surgical care over the past 40+ years, more than 97% of patients with CHD living in high-income countries are now surviving well into adulthood (Mandalenakis et al., 2020). The number of adults living with CHD (1.4 million) in the US as of 2010 surpassed the number of children (1 million) (Gilboa et al., 2016). The median age of patients with great complexity CHD in Quebec, Canada increased from 11 years of age in 1985 to 25 years of age in 2010 (Marelli et al., 2014). In an examination of mortality rates, patients with CHD who were born between 1950 and 1999 and who were alive at age 18 were extracted from a Swedish National Register and were matched with controls from the total population (Dellborg et al., 2022). At least 75% of the patients with CHD lived into their sixties (Dellborg et al., 2022). As such, CHD is now considered a lifespan condition versus a pediatric-only condition (Marelli, 2020).

Despite treatment in childhood, patients living with CHD are not cured of their disease and require lifelong cardiac care (Stout et al., 2019). They are at risk of CHD progression, which may lead to heart failure, endocarditis, arrhythmias, sudden cardiac death or need for hospitalization (Stout et al., 2019). Adult CHD (ACHD) patients are also at risk for neurocognitive decline (due exposure from circulatory anomalies in utero, surgical interventions requiring bypass and myocardial dysfunction), cancer (due to exposure of low-dose ionizing

radiation in childhood), and acquired cardiovascular disease (Marelli, 2020). Additionally, ACHD patients are at significant risk for suffering from additional noncardiac comorbidities, such as psychiatric disorders (Neidenbach et al., 2018). It is no surprise that ACHD patients with complex cardiovascular conditions are presenting as challenges for healthcare delivery (Diller, Arvanitaki, et al., 2021; Marelli, 2020). Adults with CHD, particularly those with great complexity CHD, have better outcomes when managed at accredited ACHD programs (Mylotte et al., 2014; Stout et al., 2019). To meet criteria for accreditation, an ACHD program requires specialized staff and services to best serve patients with ACHD from the point of transition, such as ACHD board certified cardiologists, cardiac anesthesiologists, electrophysiologists, interventional cardiologists, advanced cardiac imaging services as well as pulmonary hypertension services and obstetric services with expertise in ACHD, amongst others (Stout et al., 2019). In an examination of ACHD programs in Quebec, Canada between 1990 to 2005, referral to accredited ACHD programs was independently associated with a significant reduction in mortality compared with patients not receiving exclusive specialized ACHD care (hazard ratio, 0.78; 95% CI, 0.65–0.94) (Mylotte et al., 2014). The effect was mostly seen in those with great complexity CHD (hazard ratio, 0.38; 95% CI, 0.22–0.67) (Mylotte et al., 2014). In a study in Germany, ACHD patients in cardiology care had a significantly lower risk of death compared with ACHD patients who were followed by a primary care provider alone (HR 0.81, 95% CI 0.67–0.98, $p = 0.03$) (Diller, Orwat, et al., 2021).

Both the 2018 AHA/ACC and European Society of Cardiology (ESC) guidelines provide recommendations for the management of ACHD patients (including accreditation guidelines for ACHD programs, the importance of transition, and guidelines for frequency of follow-up care and testing, among others) (Baumgartner et al., 2014; Baumgartner et al., 2021; Stout et al., 2019). The guidelines recommend that patients with simple CHD either be seen at accredited ACHD programs or have collaborative planning between their general cardiology or primary

care provider and a board certified ACHD provider (Stout et al., 2019). On the other hand, all patients with moderate complexity or great complexity CHD should be cared for at accredited ACHD programs (Stout et al., 2019). These guidelines may be up for review in the future as more evidence is produced to support high morbidity even amongst defects classified as 'simple' (Eckerström et al., 2022). For example, a recent publication from Denmark noted that patients with isolated congenital ventricular septal defects are at high risk for cardiovascular morbidity across the life span, even if the defect is closed (Eckerström et al., 2022). In parallel with ACHD program expansion in Canada (Canadian Congenital Heart Alliance, 2022), and Europe (Baumgartner et al., 2014; Thomet et al., 2019), the US has also experienced ACHD program growth and there are currently 48 accredited ACHD programs (Adult Congenital Heart Association, 2022).

In summary, the ACHD population is growing. The established recommendations may need to be fleshed-out as there is increased evidence to support that all ACHD patients be seen at accredited ACHD programs. It is becoming increasingly clear that we need to transition these patients from pediatric cardiology to ACHD programs to ensure optimal outcomes.

Transition: Preparation, Transfer and Integration

Transition is the process of moving from a pediatric model of healthcare to an adult model of healthcare with, or without transfer to a new clinician (White et al., 2018). This is a gradual process with preparation starting at age 12 and continuing until after transfer to an adult model of care (A. S. John et al., 2022; Mackie et al., 2019; Moons, Bratt, et al., 2021; White et al., 2020; White et al., 2018). Transfer is the movement of care from one model of care to another, usually with a switch in clinician and clinical team (White et al., 2020). Integration is the process of a patient establishing care in an adult model of care that can fully meet a patient's complex needs (Rosen et al., 2003). Thus, the key components of transition are preparation, transfer and integration (White et al., 2018) (**Figure 1**). There are many published recommendations that

describe how to incorporate these components into practice (A.S. John et al., 2022; Moons, Bratt, et al., 2021; White et al., 2020; White et al., 2018). Patients undergoing a structured transition process, with attention to each of the phases of transition, will experience improved outcomes at each phase (White et al., 2018).

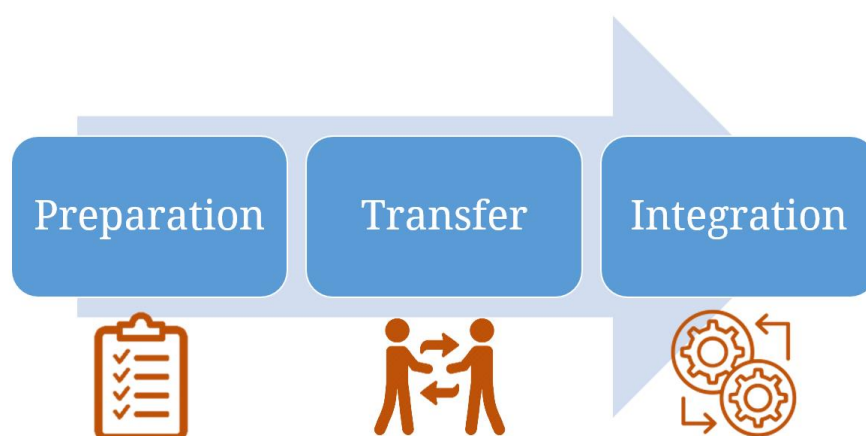


Figure 1.
The Key Components of Transition

Preparation: Transition Programs

The definition of a formal transition program is “offering education to support the medical, psychosocial, and educational/ vocational needs of adolescents as they move from the child-focused to the adult-focused healthcare system” (Blum et al., 1993). International organizations recommend that pediatric patients with CHD should undergo a structured transition process to prepare for lifelong cardiac care (A. S. John et al., 2022; Moons, Bratt, et al., 2021). Formal transition programs aim at preparing pediatric cardiology patients from age 12 and over for successful lifelong management of their chronic disease by fostering knowledge of their CHD and teaching self-management and self-advocacy skills within a structured program (A. S. John et al., 2022; Mackie et al., 2019; Moons, Bratt, et al., 2021; White et al., 2020; White et al.,

2018). International recommendations include guidance on necessary steps to take to complete the transition process (Moons, Bratt, et al., 2021) while considering social determinants of health (SDOH), psychosocial well-being, and neurocognitive status of patients within the transition process (A.S. John et al., 2022).

According to a 2016 National Survey of Children's Health, the majority of youth (12-17 years old) in the US with, or without special healthcare needs do not receive transition preparation (Lebrun-Harris et al., 2018). A multi-center study of pediatric patients with moderate or great complexity CHD in the US (n = 290, 13-30 years of age) found that 63% of respondents had never discussed transition to adult care or lifelong cardiac care with their cardiology team (Fernandes et al., 2019). In a single site study of pediatric patients with moderate or great complexity CHD in Canada (n = 82, 12-15 years of age) only 24% of patients reported discussing transition to adult care with the cardiology team (Stewart et al., 2017). Furthermore, surveys indicate that many teenagers are not concerned about transition, lack knowledge about their condition, and are unprepared for transfer to adult care (Coyne et al., 2019; Heery et al., 2015).

In a survey of 96 ACHD European programs, the presence of formal transition programs was 42% (Thomet et al., 2021). The presence of transition programs in the US are more commonplace today than they were at the turn of the century (Basile et al., 2023; Hilderson et al., 2009). In a survey of 48 pediatric cardiology clinics in North America, 71% of programs reported having a formal transition program in place (Basile et al., 2023). However, it is not clear what type of transition support youth with CHD are currently receiving within these programs and if this support meets current international recommendations (A.S. John et al., 2022; Moons, Bratt, et al., 2021). It is important to note that the European survey had a 68% program response rate (Thomet et al., 2019) compared to a 42% response rate from the North American survey (Basile et al., 2023). There is a possibility of response bias given that programs without a

transition program may have been less likely to participate in the North American survey. In the US, transition practices are shared between pediatric cardiology and ACHD programs. We do not have a current understanding of the presence of transition programs at ACHD programs in the US.

Pediatric Transition Program Outcomes

Outcomes related to transition program implementation are expanding (Schmidt et al., 2020). Transition programs have demonstrated improvements in adherence to care, improved quality of life, improved patient self-care, improved satisfaction with the health care team, improved healthcare utilization as well as improvements in some disease specific outcomes (Schmidt et al., 2020). An example of a disease specific outcomes attributed to transition program implementation are significant reductions in HbA1c in patients with Type 1 diabetes, as well as significantly reductions in diabetic ketoacidosis (DKA) admissions rates and lengths of stay of DKA admissions (Holmes-Walker et al., 2007). Although overall there is inconsistency in measuring disease-specific transition outcomes (Coyne et al., 2017). Consistency in measurement will allow us to better expand in this area of research.

CHD Transition Program Outcomes

We are also beginning to gain a better understanding of CHD transition program outcomes. In a meta-analysis by Moons and colleagues (2021) examining gaps in care during the transition years, transition programs were shown to play a role in decreasing gaps in care (12.7%; 95% CI, 2.8%–42.3%) compared with no transition programs (36.2%; 95% CI, 22.8%–52.2%); but these differences were not significant ($P=0.1119$) (Moons, Skogby, et al., 2021). Findings from this meta-analysis were limited by a lack of studies reporting transition program outcomes, and furthermore, only two of the studies were performed in the US (S. S. Gaydos et al., 2020; Hergenroeder et al., 2018) and one in Canada (Mackie et al., 2018).

Studies examining the impact of a transition program on successful transfer to ACHD care are also limited. In two studies performed in the US, post-transition intervention transfer rates to ACHD programs ranged from 35.5% to 39% (S. S. Gaydos et al., 2020; Vaikunth et al., 2018). In a cluster randomized controlled trial examining a transition program intervention versus standard care in Canada, patients in the transition program were 1.8 times more likely to have their first appointment at the ACHD program within one month compared with standard care, and this hazard increased with time (Mackie et al., 2018). A study performed by Texas Children's Hospital demonstrated that the introduction of an electronic health record-based transition planning tool and more staff to address transition activities significantly decreased time to transfer to ACHD programs in patients with moderate complexity and greater complexity CHD in comparison to the pre-intervention control group (Hergenroeder et al., 2018). Nearly a quarter (23%) of the control group experienced deterioration in scores of the New York Heart Association Functional Classification of Heart Failure over the study period, but none of the intervention group demonstrated declines in scores (Hergenroeder et al., 2018).

Studies have also shown that patients undergoing transition program interventions score higher in measures of empowerment (E.-L. Bratt et al., 2023), cardiac knowledge (E.-L. Bratt et al., 2023; Goossens, Fieuws, et al., 2015; Goossens et al., 2014; Ladouceur et al., 2017; Mackie et al., 2014; Mackie et al., 2022; Mackie et al., 2018), readiness for transfer (Mackie et al., 2018; K. Uzark et al., 2019), and self-management skills (Mackie et al., 2014; Mackie et al., 2022). Transition program interventions have also demonstrated a decreased need for parental involvement and increased satisfaction with personal appearance (E.-L. Bratt et al., 2023). In general, self-management scores amongst teenagers with CHD tend to be lower than healthy controls (Karen Uzark et al., 2019; Uzark et al., 2020), but increased knowledge about CHD and perceived self-efficacy are associated with improved psychosocial quality of life (Karen Uzark et al., 2019; Uzark et al., 2020).

CHD Transition Program Models

Different models for transition program design have been reported in the literature (**Table 1**). Nurse-led (advanced practice provider (APP) or experienced cardiology nurses) clinic-based education models have been studied in Belgium, England, France and Canada (Goossens, Fieuws, et al., 2015; Ladouceur et al., 2017; Mackie et al., 2014; Mackie et al., 2022; Mackie et al., 2018; Ricci et al., 2023). Multidisciplinary transition clinic models have been studied in the US (S. S. Gaydos et al., 2020; Vaikunth et al., 2018). A comprehensive transition program model called the STEPSTONES (Swedish Transition Effects Project Supporting Teenagers with Chronic Medical Conditions) was evaluated in Sweden within a randomized controlled trial (E.-L. Bratt et al., 2023). Studies examining program models from Canada (Mackie et al., 2014; Mackie et al., 2022; Mackie et al., 2018) and Sweden (E. L. Bratt et al., 2023) employed rigorous clinical trials (single and multicenter) and their findings, and others, are described in the section above and Table 1. The model with the highest number of transition sessions (five), and transition components (preparation and transfer) was the STEPSTONES (E. L. Bratt et al., 2023). The most frequently reported outcome measures were those examining readiness for transition (E.-L. Bratt et al., 2023; S. S. Gaydos et al., 2020; Mackie et al., 2014; Mackie et al., 2022; Mackie et al., 2018) and cardiac knowledge (Goossens, Fieuws, et al., 2015; Ladouceur et al., 2017; Mackie et al., 2014; Mackie et al., 2022; Mackie et al., 2018; Ricci et al., 2023). No program models appeared to examine integration practices into ACHD programs.

Table 1
Transition program models

Author	Study type	Interventions	Participants	Location	Session length	Measures	Results
Nurse-led							
(Mackie et al., 2022), Canada.	Single center randomized controlled trial	Introduction to transition, creation of a My Health passport, and education*	Intervention: n =30 Usual care: n=30 Ages: 13-14 years CHD: moderate or great complexity	Pediatric cardiology clinic	1) 1-hour	Primary outcome: change in transition readiness. Secondary outcome: change in cardiac knowledge.	The intervention group had significantly improved congenital heart disease knowledge and self-management skills scores, compared with the control group.
(Mackie et al., 2018), Canada.	Multi (2 sites) center clustered randomized clinical trial	1) Introduction to transition, creation of a My Health passport, education *, a review of the local ACHD cardiologists, a review of online CHD resources, and take-home materials. 2) Education *, a booklet and a review of a transition website.	Intervention: n =58 Usual care: n=63 Ages: 16-17 years CHD: moderate or great complexity	Pediatric cardiology clinic	1) 1-hour 2) 1-hour	The primary outcome: excess time to transfer to ACHD centers. Secondary outcomes: cardiac knowledge and transition readiness.	The intervention group were significantly more likely to transfer to ACHD within a month at expected time of transfer compared to the control group (HR 1.8, 95% confidence interval: 1.1 to 2.9; Cox regression, $p = 0.018$). The hazard ratio increased at six months (HR 3.0, 95% confidence interval: 1.1 to 8.3). The intervention group also had significantly higher cardiac knowledge scores and measures of transition readiness than the control group at 1, 6, 12 and 18 months.
(Mackie et al., 2014), Canada.	Single center clinical trial	Introduction to transition, creation of a My Health passport, education *, a review of the local ACHD cardiologists, a review of online CHD resources,	Intervention: n =24 Usual care: n = 26 Ages: 15 to 17 years CHD: moderate or great complexity	Pediatric cardiology clinic	1) 1-hour	Primary outcome: change in transition readiness Secondary outcome: change in cardiac knowledge. Measures were taken at one and at six months.	The intervention group had significantly improved self-management skills and congenital heart disease knowledge scores, compared with the control group.

Author	Study type	Interventions	Participants	Location	Session length	Measures	Results
		and take-home materials.	CHD or cardiomyopathy				
(Goossens, Fieuws, et al., 2015), Belgium.	Single center longitudinal study	Education*	Intervention: n = 201 Usual care: None Ages: 14-18 years CHD: all lesions	ACHD ambulatory care visit	1) 15-30 minutes	Knowledge level and prevalence of health risk behaviors Four measures taken over a 27-month period.	A small to moderate but significant increase in cardiac knowledge but no improvements in health behaviors.
(Ricci et al., 2023), United Kingdom	Single center longitudinal retrospective study	Education* Patients attend 3 transition nurse-led clinics separated by 16 months.	Intervention: n = 592 Usual care: None Ages: 12 – 21 years CHD: all lesions	Transition clinic which converted to a web-based tool due to the Covid-19 pandemic.	Not listed	Assessment of knowledge and self-care skills. Measures were taken three times, separated by 16 months. Factors that are associated with a successful transfer to ACHD.	Significant improvements in knowledge from the first to the second visit and from the second to the third. Half of the sample transferred to ACHD, Younger age at first visit, simpler CHD and absence of physical disability were associated with successful transfer.
(Ladouceur et al., 2017). France	Single center descriptive cross-sectional study	Assessment of barriers and high-risk behaviors, education*, referral of high-risk patients for further clinical management, introduction to transition, resources including a health passport and a video game to improve CHD knowledge	Intervention: n = 22 Usual care: n = 93 Ages: 14-19 years CHD: all lesions	Pediatric cardiology clinic	Not listed	Knowledge scores.	The mean cardiac knowledge score was significantly higher in the intervention group compared to the control group.
Multidisciplinary							
(S. S. Gaydos et al.,	Single center retrospective case	Overview of transition and its importance, a folder containing a	Intervention: n = 53 Usual care: n= 54	Transition Clinic	Not listed	Primary outcome: lost to follow up' (absence of cardiac care at six months	Gaps in care were significantly lower in the intervention group compared to the control (7.3% vs 25.9% respectively, p<0.01).

Author	Study type	Interventions	Participants	Location	Session length	Measures	Results
2020), US	control study	welcome letter, a diagram of their cardiac defect as well as CHD resources, education*, and an opportunity to meet with an ACHD team member.	Ages: 11 years of age and older CHD: all lesions			beyond the recommended timeframe). Secondary outcome: transition readiness, QOL and referral to ACHD. Measures of readiness assessment and QOL were provided at the transition clinic visit as well as withing a 6-month interval.	A third of the patients transferred to ACHD and readiness for transfer to ACHD was associated with older age.
(Vaikunth et al., 2018), US	Single center retrospective analysis	Assessments of readiness and resources to help navigate the physical transfer. Patients are scheduled for appointments in the ACHD clinic.	Intervention: n = 73 Usual care: none Ages: 18-21 years CHD: all lesions	Transition clinic	Not listed	Transfer to ACHD	Thirty percent of the study patients transferred to the ACHD center. Severe congenital heart disease (OR 4.44, 95% CI 1.25-15.79, P 5 .02) and presence of a cardiac implantable electronic device (OR 4.93, 95% CI 1.18-20.58, P 5 .03) correlated with transfer.
Comprehensive							
(E.-L. Bratt et al., 2023), Sweden	Multicenter RCT embedded in a longitudinal observational study	1) OP visit with transition coordinator (TC). 2) Repeat OP visit with TC. 3) Information Day for youth, families and introduction to the adult team. 4) Repeat OP visit with TC. 5) Transfer.	Intervention: n= 54 Usual care: n= 60 Contaminati on check: n= 40 Ages: 16 years CHD: all lesions	7 CHD centers in Sweden. 2: intervention groups and 5: 'contaminati on check control groups'	Not listed	Primary outcome: measure of patient empowerment. Secondary outcomes: transition readiness, health behaviors, QOL, and patient reported health. Parents: measures of transition readiness and parental uncertainty toward transition.	Primary outcome: Change in empowerment was significantly higher in the intervention group. Secondary outcomes: Significant differences in the intervention group over time for decreased parental involvement, increased knowledge about condition and increased satisfaction with personal appearance.

* teaching: see Table 2

Abbreviations: QOL = quality of life, OP = outpatient, TC = transition coordinator.

Transition programs activities and education topics varied between studies and program models. See **Table 2** for a breakdown of transition education topics by study. The most frequently reported education topics were those related to ‘the heart defect’ (E. L. Bratt et al., 2023; S. S. Gaydos et al., 2020; Goossens, Fieuws, et al., 2015; Ladouceur et al., 2017; Mackie et al., 2014; Mackie et al., 2022; Mackie et al., 2018; Ricci et al., 2023) and ‘current treatment and medications (E. L. Bratt et al., 2023; S. S. Gaydos et al., 2020; Goossens, Fieuws, et al., 2015; Ladouceur et al., 2017; Mackie et al., 2014; Mackie et al., 2022; Mackie et al., 2018; Ricci et al., 2023).’ The least commonly reported education topic was ‘health insurance’ (Ricci et al., 2023). Vaikunth and colleagues (2018) did not report utilizing education in their study.

Table 2

Transition Education Topics by Study

	(Mackie et al., 2022)	(Mackie et al., 2018).	(Mackie et al., 2014)	(Goossens, Fieuws, et al., 2015)	(Ladouceur et al., 2017)	(Ricci et al., 2023)	(S. S. Gaydos et al., 2020)	(Vaikunth et al., 2018)	(E.-L. Bratt et al., 2023)
Heart Defect	x	x	x	x	x	x	x		x
Current treatment/ Medications	x	x	x	x	x	x	x		x
Symptoms /complications	x	x	x		x	x	x		x
Need for follow-up				x	x	x			x
Infective endocarditis/dental		x	x	x	x	x	x		
Healthy lifestyle/sports and limitations				x	x	x	x		x
Vocational and educational choices				x	x	x			x
Sexuality and inheritability of the defect		x	x		x	x	x		
Risks associated with contraception and pregnancy		x	x	x	x	x	x		
Prevention/ risky behaviors		x	x	x	x				
Communication with the team	x	x				x			x
Health insurance						x			
Goal setting		x					x		x
Turning 18 and age-appropriate strategies	x	x					x		x
Mental health	x								x

In summary, we do not have a clear understanding of what type of transition support youth with CHD are currently receiving within transition programs in the US and if this support meets international recommendations (A.S. John et al., 2022; Moons, Bratt, et al., 2021). We also do not have an understanding of transition practices within ACHD programs in the US. In general, CHD transition programs appear to lead to many improved outcomes but there is not sufficient evidence to show that transition programs support effective transfer to ACHD programs, especially in the US (S. S. Gaydos et al., 2020; Vaikunth et al., 2018). It is difficult to determine which transition program model and transition practices are the most effective as our findings are limited by a small number of studies, heterogeneity in program models and outcome measures and a lack of studies comparing program approaches. Finally, no transition models appeared to incorporate integration practices into ACHD programs.

Transfer to ACHD

As mentioned previously, transfer is the movement of care from one model of care to another, usually with a switch in clinician and clinical team (White et al., 2020). It is recommended that pediatric patients with CHD transfer to ACHD programs at around 18 to 21 years of age (A.S. John et al., 2022; Moons, Bratt, et al., 2021; White et al., 2020; White et al., 2018). Transfer policies and practices vary internationally though. In Europe, some programs transfer patients to ACHD care earlier, at around age 16 (Goossens et al., 2011) or age 18 (Skogby et al., 2020). In the US patients are more likely to be transferred at a later age, if at all (Bohun et al., 2016). In the US, between 11-39% of CHD patients transfer to accredited ACHD programs (Bohun et al., 2016; S. S. Gaydos et al., 2020; Gerardin et al., 2019; Goossens, Fernandes, et al., 2015; Harbison et al., 2016; Kollengode et al., 2018; Norris et al., 2013; Vaikunth et al., 2018). Higher transfer rates are reported in Canada and Europe (Goossens et al., 2011; Mondal et al., 2020; Reid et al., 2004; Skogby et al., 2020). Canada has the highest reported transfer rate to ACHD

programs at 96.4% (Mondal et al., 2020), followed by Sweden at 79.7% (Skogby et al., 2020) and Belgium at 77.2% (Goossens et al., 2011). Factors associated with successful transfer to ACHD care include greater complexity CHD (Bohun et al., 2016; S. S. Gaydos et al., 2020; Gerardin et al., 2019; Goossens, Fernandes, et al., 2015; Harbison et al., 2016; Kollengode et al., 2018; Norris et al., 2013; Vaikunth et al., 2018), insurance (Bohun et al., 2016; Vaikunth et al., 2018), referral to the ACHD team (Bohun et al., 2016; Reid et al., 2004), presence of a cardiac implantable electronic device (Vaikunth et al., 2018), being on cardiac medication (Harbison et al., 2016; Kollengode et al., 2018), prior cardiac surgery (Harbison et al., 2016; Reid et al., 2004), presence of comorbidities (Vaikunth et al., 2018), older age (Reid et al., 2004), and educational interventions emphasizing lifelong cardiac care (S. S. Gaydos et al., 2020; Kollengode et al., 2018). A far distance to the referral center has shown to either have no effect on transfer outcomes (such as successful transfer to ACHD centers or gaps in care) (Bohun et al., 2016; Goossens, Fernandes, et al., 2015; Goossens et al., 2011; Harbison et al., 2016) or to negatively impact transfer outcomes in the US (Gerardin et al., 2019; Mondal et al., 2020; Reid et al., 2004). Studies from Canada, however, have consistently demonstrated that distance from the referral program negatively impacts transfer outcomes (Mondal et al., 2020; Moons, Skogby, et al., 2021; Reid et al., 2004).

Transfer rates of pediatric cardiology patients to ACHD programs are reported to be higher in countries with universal health insurance, larger specialized CHD programs, location and affiliation between pediatric cardiology and ACHD services, and programs with streamlined transfer processes (Vonder Muhll, 2020). The Affordable Care Act was fully implemented in the US in 2014, allowing greater healthcare insurance coverage (dependent coverage to age 26 and removal of preexisting condition exclusions and caps in reimbursement). Despite these advances, transfer rates to ACHD programs in the US remain low, indicating that having insurance coverage does not necessarily guarantee ongoing care (A.S. John et al., 2022).

In a survey of US and European programs in 2006, mandatory transfer practices to ACHD programs were only reported in about 16% of US programs compared to 85% of European programs (Hilderson et al., 2009). According to the survey findings, structured transfer processes were reported at 68% of surveyed US programs compared with 85% of European programs (Moons, Skogby, et al., 2021). In an updated 2017 survey of 96 ACHD programs in Europe, structured transfer processes were reported to be slightly higher at 88.5% (Thomet et al., 2021). There is currently no updated data on transfer practices in the US. In summary, fewer patients appear to successfully transfer to ACHD programs in the US compared with other countries. More research is needed to explore current transfer practices in the US so that interventions can be designed to optimize the transfer process.

Integration

The transition process is complete when patients are fully integrated into adult care (Coyne et al., 2017; Moons, Bratt, et al., 2021; White et al., 2018). Successful integration is dependent on a thorough and structured transfer process which includes communication between pediatric cardiology and ACHD programs and patient and parent preparation for the differences between adult and pediatric models of care (A.S. John et al., 2022; Moons, Bratt, et al., 2021). Integration practices aim at helping patients adjust to an adult model of care and ensuring ongoing care (White et al., 2020). Some practices may be unprepared to manage young adults, especially those with complex health care needs as few providers receive training about transition, and managing needs associated with the young adult years (Cooley et al., 2011). In studies of patients experiences when transferring to ACHD care, some describe the integration period as taking time to adjust to the new relationships (Catena et al., 2018), others perceive a desire for continuity in the quality of care they received in pediatric cardiology care, a young adult focus, individualized care, and for parents to remain involved in a supportive capacity (Heery et al., 2015). In the US transition activities take place in both pediatric cardiology and ACHD

programs. Some programs share a clinic space and other programs are located separately. We do not have a current understanding of how these structural differences and relationships impact transition activities and transition outcomes as well as patient and family experiences. As mentioned previously, there do not appear to be any studies that explore ACHD integration practices. In summary, more research is needed to explore integration practices into ACHD programs with attention to practices that support continuity in care, integrated services between all aspects of care, and services designed to reduce barriers to ongoing care.

Barriers to Successful Transition

There are numerous barriers to a successful transition. The main barriers are the time and resources needed to perform transition practices, as well as no best identified models for delivering these practices (A.S. John et al., 2022). According to patients and families and healthcare providers in a 2017 study of perceived barriers preventing a successful transition in the US, the interinstitutional transfer process, the lack of formal transition programs and the complex navigation of the health care system were among the barriers listed (Everitt et al., 2017). Despite this, health care system factors that may influence successful transfer to ACHD care are understudied, even though they are reported to influence transition outcomes (Goossens et al., 2016; Skogby et al., 2020). Added barriers include retention in pediatric cardiology care, lack of accredited ACHD programs, challenges related to adolescence, and patients with developmental or psychiatric disorders, among others. These are described in more detail below.

Retention in Pediatric Cardiology

Studies in the US show that retention of patients in pediatric cardiology who are over the age of 18 ranges from 21% to 69% (Bohun et al., 2016; Gerardin et al., 2019; Goossens, Fernandes, et al., 2015; Harbison et al., 2016; Kollengode et al., 2018; Norris et al., 2013). Because some European centers favor earlier transfer to ACHD, retention in pediatric cardiology is not as

common in Europe (Goossens et al., 2011; Skogby et al., 2020). Perceived patient and parent barriers to transferring to ACHD centers in the US include limited access to an ACHD specialist, pediatric cardiologist attachment, lack of understanding or negative perceptions of ACHD care, lack of healthcare insurance, not feeling equipped for transfer, and not knowing that ACHD care is necessary (Fernandes et al., 2012; L. M. Gaydos et al., 2020; Ko et al., 2021). A lack of mandatory transfer practices to ACHD programs in the US are also likely to contribute towards retention in pediatric cardiology care (Hilderson et al., 2009).

Lack of Staff

As of 2016 there were 115 identified ACHD programs in the US and 320 board-certified ACHD cardiologists (Ezzeddine et al., 2019). It is estimated that an additional 170 ACHD board-certified physicians and 48 ACHD programs are needed to maintain adequate physician-to-patient ratios and meet the demands of the growing patient population (Ezzeddine et al., 2019). In comparison, as of 2015 there were reported to be 2,521 pediatric cardiologists in the US based on the Physician Specialty Data Report (The Association of American Medical Colleges, 2015). There are regional differences in ratios of ACHD board-certified physicians-to-patients, with the District of Columbia being best served and Indiana being worst served (Ezzeddine et al., 2019). In a 2016 survey of 96 European programs, only four programs met the European Society of Cardiology staffing requirements for ACHD programs (Thomet et al., 2019). In the US, transition programs are housed within pediatric cardiology and ACHD programs. Current staffing practices in the transition programs in the US are unknown and are in need of further research.

Adolescence and special health care needs

Adolescence is marked by growing independence and self-determination (Hemker et al., 2011). Adolescents have a developing frontal lobe which controls decision making and high-risk behaviors which take until the mid-20's to fully develop (Colver & Longwell, 2013). For children

with chronic disease this process takes longer (Colver & Longwell, 2013). Adolescence for children with chronic disease is a time of high emergency department use, peaking of health risk behaviors, exacerbation of chronic conditions and low health care maintenance, especially in males (Hemker et al., 2011). Adding to these challenges, there is a decline in adult type behaviors seen in seven large nationally representative surveys of US adolescents from 1976 to 2014 (Twenge & Park, 2019). Findings revealed that fewer adolescents are engaging in adult type behaviors such as owning a driver's license, trying alcohol, going on a date or working for pay (Twenge & Park, 2019).

Adolescents with developmental and/or intellectual disabilities face additional obstacles when transitioning from pediatric to adult care as system supports and accommodations are often lacking (Kovacs & Bellinger, 2021; Kovacs et al., 2009; Kovacs & Utens, 2015; van Schalkwyk & Volkmar, 2017). Patients who are unable to fully participate in health-related decision making may require decision support, or in some cases undergo a legal process for parents or caregivers to obtain legal guardianship (White et al., 2018). This process should be started at around age 17 years and communicated with the adult care team (White et al., 2018). These patients may also require an adjusted transfer process including adjusted timing of transfer, the addition of condition specific protocols, additional care coordination and resources for support and more (White et al., 2018).

Patients with CHD are at greater risk for a developmental disorder, disabilities and developmental delay (Kovacs & Bellinger, 2021; Kovacs et al., 2022; Marino et al., 2012). According to White and Cooley (2018), mental health conditions often peak during the emerging adult years impacting self-care and participation in routine medical and mental health care as well as decision-making. According to a meta-analysis by Abda and colleagues (2018), 25% of pediatric patients with CHD present with behavioral difficulties, more so than healthy peers (Abda et al., 2019). Gonzalez and colleagues (2021) discovered that CHD patients 10 to 17

years of age are two to three times more likely to suffer from anxiety or depression compared with the average pediatric population (Gonzalez et al., 2021). Psychological challenges persist into adulthood and psychiatric disorders are the most common comorbidity among ACHD patients creating a strong need to integrate mental health professionals into CHD care (Kovacs et al., 2022). It is not currently known what type of supports patients with developmental and/or intellectual disabilities are currently receiving in transition programs. In summary, there are numerous barriers that may impact successful transition to ACHD programs, with the most prevalent being time and resources to complete transition practices, and no best models for delivering transition practices. Addressing these barriers is important as patients who do not successfully transition into ACHD programs are at risk of experiencing gaps in care.

Gaps in Care

Those who experience gaps in care during the transition years are at risk for developing complications requiring more frequent visits to the emergency department, hospitalization and procedural intervention (de Bono & Freeman, 2005; Gurvitz et al., 2007; Iversen et al., 2007; Wacker et al., 2005; Yeung et al., 2008). In fact, patients who experience a lapse in care during the transition years are about 3 times [OR 3.1, 95% CI: 1.5, 6.8] more likely to require urgent cardiac intervention compared to those with no lapse (Yeung et al., 2008). Patients with CHD who live in the US experience higher rates of gaps in care during the transition years (34%; 96% CI, 24.3% - 45.4%) compared with those in Canada and Europe ($p = 0.0004$). Factors associated with gaps in CHD care during the transition years include a diagnosis of simple CHD, lack of patient and family preparation to transition, cognitive or psychosocial impairments, patient and provider attachment, lack of transition program integration, and increased distance from a (A)CHD program (Fernandes et al., 2012; Gurvitz et al., 2013; Moons, Skogby, et al., 2021; Williams, 2015). Factors that appear to reduce the likelihood of gaps in care include beliefs that specialized care is necessary, poorer health status, independence in attending

pediatric appointments (without parents), and referral to ACHD programs (Heery et al., 2015). Programs within the US that report fewer gaps in care attribute likely success to their center's model of care structure, which includes continuous care, integrated services between all aspects of care, and services designed to reduce barriers to ongoing care (Evans et al., 2022).

Gaps in research

CHD is a lifespan disease and transition programs are necessary to support optimal outcomes during the transition years and beyond. We need more studies that examine transition practices in the US with attention to each of the transition components (preparation, transfer and integration). Within preparation, more studies are needed to strengthen our understanding of the best methods for delivering transition practices, as well as understanding the impact these practices have in the long term, such as on patient preparation and successful transfer and integration into ACHD programs. We are in need of rigorous studies that utilize consistent outcome measures that compare transition program models and approaches so that we can gain a better understanding of how to best deliver transition practices. We also do not have a current understanding of transition practices in the US, or the presence of formal transition programs at ACHD programs in the US. Within transfer, the adoption of systematic transfer processes to ACHD centers, which are common in Europe and a component of a transition program, are understudied within the US context. More research is needed to explore current transfer practices in the US so that interventions can be designed to optimize the transfer process. We are also in need of studies that examine how existing transfer practices may impact transfer outcomes, such as transfer occurrence or time-to-transfer to ACHD programs. Within integration, there appear to be no CHD transition program models that incorporate integration practices. We need to explore integration practices in the US, and internationally, so that we can have a better understanding of how to integrate these into structured transition

processes. We also need to examine the outcomes of these practices, such as in their ability to support continuity in care and decrease gaps in care.

Theoretical Framework

The Six Core Elements Approach™

A national initiative on health care transition, the National Alliance to Advance Adolescent Health, in partnership with the Maternal and Child Health Bureau, created the Got Transition/Center for Health Care Transition Improvement (Got Transition, 2014). Got Transition’s Six Core Elements of Health Care Transition™3.0 was developed based on the 2018 Clinical Report on Health Care Transition from the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians (White et al., 2020; White et al., 2018).

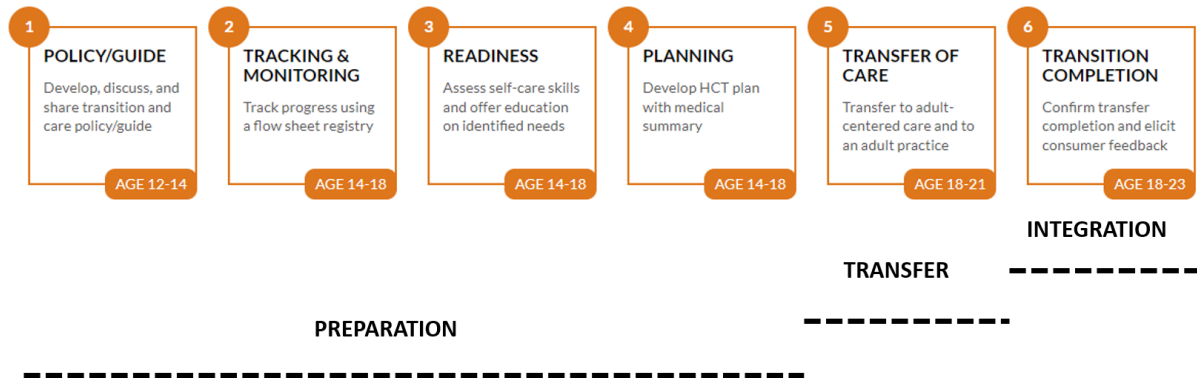


Figure 2
Six Core Elements™

The Six Core Elements™ are housed under three transition components: preparation, transfer, and integration (White et al., 2020). The elements include 1) creating a transition policy/guide, 2) tracking and monitoring progress, 3) assessing transition readiness, and 4) planning for adult care, 5) transfer of care and 6) integration into adult care. The following goals drive this

approach: “1) to improve the ability of youth and young adults with and without special health care needs to manage their own health care and effectively use health services, and 2) to ensure an organized process in pediatric and adult health care practices to facilitate transition preparation, transfer of care, and integration into adult-centered health care.” The Six Core Elements™ provides us with the basic components of a structured transition process which can be customized to different care settings, as well as subspecialties (White et al., 2020). We utilized this approach in this program of research to examine current CHD transition practices, find methods to overcome transition barriers and address gaps in the research within each transition component (preparation, transfer and integration).

Purpose of this Dissertation

Patients with CHD require uninterrupted lifelong specialized cardiac care, yet the transition years are a vulnerable time for these patients. Transition programs offer structured support to patients with CHD with the aim of improving CHD knowledge, independence in care, and providing an uninterrupted transfer process and integration into accredited ACHD programs. The main barriers to successful transition program implementation are time and resources to complete transition activities and there is no best model for transition programs. Patients with CHD in the US are more likely to experience gaps in care during the transition years and less likely to transfer to ACHD programs compared with Canada and Europe. There is need for expanded research in the US within each of the transition components (preparation, transfer and integration) so that we can develop methods to address transition barriers and gain a better understanding of current transition practices. The purpose of this dissertation is to test a low resource intervention to facilitate patient preparation, identify factors that improve effective transfer, and evaluate transition practices at ACHD programs in the US.

Proposed Aims

To address the purpose of this dissertation the following three aims were set forth towards achieving this purpose:

1. To test a low resource transition activity for pediatric patients with congenital heart disease in the pediatric cardiology ambulatory care setting.
2. To quantify differences in time to transfer to ACHD centers between patients with moderate and great complexity CHD who received a referral order versus those who did not.
3. To characterize ACHD transition practices across the US.

The aims are described in a manuscript style dissertation with the goal to disseminate science in three manuscripts and provide clinician opportunities to consider the findings and potentially implement strategies to address them. The manuscript titles for each aim are enumerated below:

Aim	Proposed Manuscript Title
# 1	A medical assistant - facilitated transition activity in a pediatric cardiology clinic
# 2	Referral order placement decreases time to transfer to adult congenital heart disease care
# 3	Congenital Heart Disease Transition Practices in the United States: A survey of adult congenital heart disease programs

Implications for Practice

The collective body of work set forth in this program of research will explore methods within each transition component to see if we can overcome some of the transition barriers and address some of the gaps in research. We will address some of the transition barriers by examining an alternative low resource transition model to aid in patient preparation: a medical assistant (MA) facilitated transition activity. We will examine this activity's ability to increase the presence of documented transition discussions in the pediatric cardiology clinic without the use of additional resources such as staff, and clinic space. We will also test a second low resource intensive practice: placement of a referral order to see if it leads to improved transfer outcomes

to ACHD programs, such as transfer occurrence and time to transfer. These findings maybe important as we mentioned that patients with CHD in the US experience lower percentage of transfer to ACHD programs and experience higher rates of gaps in care during the transition years compared with Canada or Europe.

We will address a gap in the research by exploring the presence of formal transition programs and practices at surveyed ACHD programs in the US. We will also address a gap in the research by exploring the presence of structured transfer processes for CHD patients in the US from the perspectives of these surveyed programs. Our survey will be the first to explore integration practices into ACHD programs in the US and internationally and it may provide us with a benchmark of transition practices in the US. With this, we can generate amenable targets for intervention to optimize transition practices across settings.

Summary

The collective body of research set forth in this program of research studies the impact of a low resource transition intervention in the US setting, provides an examination of factors which may improve transfer outcomes, as well as an examination of current transition practices at ACHD programs in the US. The low resource intervention that was tested in the program of research is the feasibility of a MA-facilitated transition activity in the pediatric cardiology clinic. We also examined time to transfer to ACHD programs following referral order placement versus no referral order placement. Lastly, we surveyed US ACHD programs to learn more about transition practices.

CHAPTER II

A medical assistant-facilitated transition activity in a pediatric cardiology clinic

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dissemination of clinical practice exemplars and innovations. The Health Care Transitions Journal has no measured an Impact Factor as it launched in May 2023.

Abstract

Background: Formal transition programs prepare pediatric patients with congenital heart disease (CHD) for successful lifelong management of their disease. Conducting transition program activities in pediatric cardiology clinics can be a challenge if there are limited resources. The purpose of this study was to test the effectiveness of a medical assistant (MA)-facilitated transition activity in increasing transition discussions and characterize staff acceptability of this intervention.

Method: We performed a prospective exploratory study over a five-week period. CHD patients aged 13 and older presenting for routine pediatric cardiology follow-up appointments received a prompt from the MA to view a transition tool and select topics to discuss with the pediatric cardiologist during the clinic visit. Historical control group data were collected from the same period, two years prior. We compared the presence of documentation of transition discussions between the transition activity and control group using comparative statistics. Staff acceptability was assessed using the revised Treatment Acceptability and Preference Questionnaire.

Results: A total of 14 staff members participated in the transition activity involving 29 patients. Significantly more transition discussions were documented in the transition activity group compared with the historic control group ($p < 0.001$). Patients discussed more transition topics (median = 5, Interquartile range 2-7) than what was requested (median = 2, Interquartile range 1-4). All staff rated the activity as acceptable (ranging from 'somewhat acceptable' to 'very much acceptable') and were willing to continue after the study ended.

Conclusion: Having an MA-facilitated transition activity increased documentation of transition discussions in the pediatric cardiology clinic. Staff were accepting and in favor of continuing this low-resource activity.

Introduction

Formal transition programs aim at preparing pediatric patients with congenital heart disease (CHD) for successful lifelong management of their chronic disease by fostering knowledge of their CHD and self-management and self-advocacy skills (A. S. John et al., 2022; White et al., 2018). These programs are important because many teenagers lack knowledge about their condition and are unprepared for transfer to adult care (Coyne et al., 2019), and a lack of transition education is associated with decreased self-efficacy and self-management skills (Uzark et al., 2015). Additionally, increased patient preparation may alleviate anxiety and uncertainty surrounding the transfer process to adult care (de Hosson et al., 2021). Moreover, pediatric patients with CHD are also interested in learning about transition topics and understanding their heart defects and cardiac surgeries (Lopez et al., 2015). Formal transition programs have demonstrated improvements in adherence to care, improved quality of life, improved patient self-care, improved satisfaction with the health care team, and improved healthcare utilization (Schmidt et al., 2020). This preparation is best if started between 12-14 years of age (A.S. John et al., 2022).

Even though we know that transition programs are effective, how best to deliver these programs remains undetermined (A.S. John et al., 2022). Conducting transition program activities in pediatric cardiology clinics can be a challenge if there is limited clinic space, time, and staff to perform these activities (A.S. John et al., 2022). Expanded roles for medical assistants (MAs) have been explored in the primary care setting with intentions to decrease physician workload and improve patient care (Chapman & Blash, 2017). For example, MAs serving as health coaches resulted in improved diabetes and lipid management in low-income patients (Willard-Grace et al., 2015). In pediatric cardiology, MAs may be able to facilitate transition discussions by introducing a transition tool that prompts discussions between the patient and the healthcare team. By facilitating transition discussions, MAs may alleviate the need for additional resources

to perform transition activities. The purpose of this study was to test the effectiveness of increasing discussion about transition and characterize staff acceptability of a MA-facilitated transition activity in the ambulatory care setting.

Methods

Study Design

We performed a prospective exploratory study of a MA-facilitated transition activity in a pediatric cardiology clinic located in a tertiary medical center. The study took place over a five-week period from June to July 2023. Control group data were collected by retrospective review over a five-week period from the same time period as the study but two years prior. Transition discussions for the control group took place at the discretion of the pediatric cardiologist and they may or may not have been documented in the medical record. At the end of the study, staff completed a questionnaire about their acceptance of the transition activity. The study was approved by the Oregon Health & Science University Institutional Review Board. A consent information sheet was attached to the staff questionnaire and completion of the questionnaire implied informed consent.

Sample

Our target staff population was comprised of MAs (n = 2), pediatric cardiologists (n = 12), pediatric cardiology fellows (n = 2), advanced practice providers (n = 3) and pediatric cardiology nurses (n = 3) who provided care for patients eligible for transition per standard clinical practices and met the following criteria: English-speaking, age 13 and older, and presenting for routine pediatric cardiology follow-up appointments for CHD. Patients with a history of heart transplants were also included in the study. Patients with documentation of moderate or severe developmental delay on their problem list in the medical record were excluded from the study. Detailed characteristics of the staff sample were not obtained to protect the identity of the participants.

Procedures

The study was presented by one member of the research team at a pediatric cardiology division meeting. MAs and pediatric cardiology nurses also attend the division meetings. Those who were unable to attend the division meeting received individual education. A script was developed for the MA team to use when presenting the study to patients. A standard electronic health record phrase was developed for the MA team to record the patient and provider transition discussion in the electronic medical record. Using scripted prompts, MAs instructed patients to review a transition handout containing 17 transition related topics. The handout was developed by Uzark and colleagues (2015) to guide transition discussion between the patient, family member(s), and the pediatric cardiologist (Uzark et al., 2015). The MA prompted patients to circle the transition topic(s) of interest, which was then given to the pediatric cardiologist. The pediatric cardiologist indicated which transition topics were discussed during the visit and the completed transition encounter was documented in the clinic note by the MA.

Data Collection

Our primary outcome of interest was documentation of a transition discussion during the clinic visit. Control group (i.e., historical) data was collected from a retrospective medical record review for the presence of documentation of transition discussions in the office visit note. We collected baseline patient data including age, sex and primary cardiac diagnosis. We then grouped patients' cardiac anatomy by the 2018 American Heart Association (AHA) / American College of Cardiology (ACC) guideline for the management of adults with CHD ACHD Anatomic and Physiological (AP) classification system as simple, moderate complexity and great complexity CHD (Stout et al., 2019). Patients with a history of heart transplants were grouped separately.

Outcomes

Staff outcomes included staff acceptance of the transition activity. Perceived staff acceptability of the activity was measured by the acceptability portion of the revised Treatment Acceptability and Preference Questionnaire, which has demonstrated reliability and validity (Sidani, Epstein, et al., 2009). The measure of acceptability includes four subscales: effectiveness (i.e., does the activity achieve its goal), appropriateness (i.e., is the activity logical and reasonable), suitability (i.e., for the clinic setting) and willingness to comply (Sidani, Epstein, et al., 2009). The questionnaire also contains an additional measure of risk (i.e., did the activity produce any adverse effects). Each of the subscales are rated on a five-point scale, ranging from not at all (0) to very much (4). Scores were computed for each subscale and for the overall acceptability of the activity, with higher scores indicating more acceptability. The questionnaire contained an additional open-ended question: is there anything else you want to tell us? Questionnaires were emailed to staff members at the end of the study using the Qualtrics platform (Qualtrics, Provo, UT).

Data Analysis

Standard descriptive statistics of frequency, central tendency, and dispersion were used to describe the findings. Independent t-test were used to test the difference between the number of transition topics documented between the transition activity group and the historical control group. Independent t-tests were also used to test the differences between the number of transition discussions that patients in the transition activity group requested and the number that were addressed during the clinic visit. Individual and a total scale score retrieved from the completed revised Treatment Acceptability and Preference Questionnaire were computed as the mean of the items' scores to reflect level of perceived treatment acceptability. SPSS version 28 (IBM, Armonk, NY) was used to perform data analyses.

Results

A total of 33 patients met inclusion and exclusion criteria to receive the MA-facilitated transition activity, and of that sample, 29 patients were involved (Figure 1). The mean age of patients receiving the activity was 16.3 ± 1.8 years, ranging between 13- 20 years of age. Half of the sample (52%) were male. In an examination of CHD anatomy, one patient had simple complexity, 18 patients had moderate complexity, and eight patients had great complexity CHD anatomy. Two patients had undergone heart transplantation. A total of 24 patients were eligible for the retrospective control group. Of our sample of 22 staff members, 14 participated in the transition activity including MAs (n = 2), pediatric cardiologists (n = 6), pediatric cardiology fellows (n = 2), advanced practice providers (n = 2), and cardiology clinic nurses (n = 2).

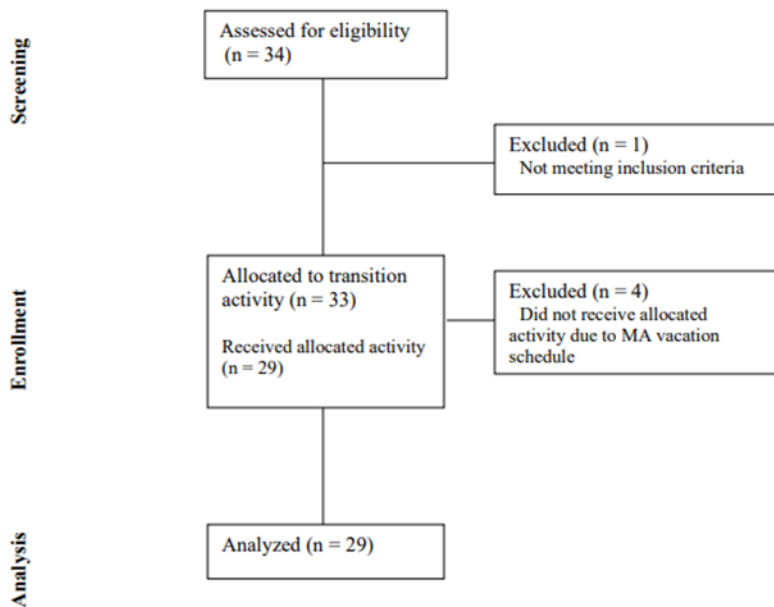


Figure 1
Transition Activity Group Sample Screening, Enrollment, and Analysis

Transition discussions

There were significant differences in the total number of documented transition topics between the transition activity group and the retrospective control group (143 topics discussed across 29 patient visits vs 1 topic discussed across 24 patient visits, respectively, $p < 0.001$). Notably, the transition activity group discussed significantly more transition topics (median 5 [interquartile range 2-7]) than what was requested on the transition handout (median 2 [interquartile range 1-4]; $p < 0.001$). ‘The name of your heart condition and any surgeries’ (38%) and ‘The names of your medications and what they are used for’ (35%) were the top two requested and discussed topics. (Table 1).

Table 2
Transition Topics Requested and Discussed, n = 29

Transition activity group	Requested	Discussed
The name of your heart condition and any surgeries	11 (37.9%)	17 (58.6%)
The names of your medications and what they are used for	10 (34.5%)	17 (58.6%)
Symptoms or problems doctor needs to know about	8 (27.6%)	11 (37.9%)
How to talk with your doctor and ask questions	0	8 (27.6%)
How to contact your heart doctor or nurse	7 (24.1%)	13 (44.8%)
If you need antibiotics for dental work	3 (10.3%)	6 (20.7%)
How to take your medications correctly without help	1 (3.4%)	2 (6.9%)
Exercise or sports recommendations	6 (20.7%)	8 (27.6%)
How to talk to friends and others about your heart	3 (10.3%)	3 (10.3%)
Future needs for cardiology visits	10 (34.5%)	11 (37.9%)
How pregnancy might affect your heart and your baby	3 (10.3%)	5 (17.2%)
How to prevent pregnancy with the safest birth control	2 (6.9%)	3 (10.3%)
How to refill your prescriptions	5 (17.2%)	8 (27.6%)
How to make your appointments	7 (24.1%)	11 (37.9%)
How to manage your stress	4 (13.8%)	5 (17.2%)
Job or vocational counseling	3 (10.3%)	5 (17.2%)
Health insurance needs when not covered by your parents	8 (27.6%)	10 (34.5%)

Acceptability

Of the 14 staff members who participated in the study, a total of 11 (79%) completed the acceptability portion of the revised Treatment Acceptability and Preference Questionnaire (Sidani, Miranda, et al., 2009) (Table 2). The acceptability of the activity was rated by all staff members as somewhat acceptable to very much acceptable (score mean 3.23±0.3). Medical assistants ranked all questions as ‘very much acceptable.’ All staff ranked the activity as ‘not at all’ for risk. Staff responses demonstrated a willingness to utilize the activity on an ongoing basis. Two staff members provided responses to the open-ended question, “Is there anything else you want to tell us?”

- Staff member #1: *“Not sure how effective it will be in preparing teenagers for transfer but is an excellent tool.”*
- Staff member #2: *“Young adolescents are very difficult to reach in terms of planning ahead. It would be great to design an incentive.”*

Table 2
Staff Acceptability of the Transition Activity

	Mean (SD)
Effectiveness	
How effective, in the short-term, do you think this activity is in increasing transition discussions with teenagers/ young adults with congenital heart disease in the pediatric cardiology ambulatory clinic setting?	3.36 (±0.51)
How effective, in the long-term, do you think this activity will be in increasing transition discussions with teenagers/ young adults with congenital heart disease in the pediatric cardiology ambulatory clinic setting?	3.45 (±0.52)
How effective do you think this activity is in preparing teenagers/ young adults with congenital heart disease for transfer to adult congenital heart disease care?	2.82 (±0.98)
How effective do you think this activity is in improving your ability to perform your daily usual clinic activities?	2.82 (±0.87)
Appropriateness	
How acceptable / logical does this activity seem to you?	3.5 (±0.53)
How suitable/appropriate is this activity for the pediatric cardiology ambulatory clinic setting?	3.55 (±0.52)
Risk	
In your opinion, how severe (bad) are the risks of this activity (such as increased stress on staff or patients and families)?	0.00
Suitability	
How easy is it to apply this activity in the pediatric cardiology ambulatory clinic setting?	3.09 (±0.83)
Willingness to adhere	

How willing are you to utilize this activity on an ongoing basis?	3.45 (±0.69)
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Abbreviations: SD, standard deviation.
Scale: 0 = not at all; 4 = very much [13].

Discussion

In this study, we tested the effectiveness of a MA-facilitated transition activity in increasing discussion about transition, as well as staff acceptability of the intervention, in the pediatric cardiac ambulatory care setting. This intervention significantly increased the number of documented transition topics as compared with the number of topics documented in a similar cohort two years prior. We also found that the transition activity led to more transition discussions during the cardiology clinic visit compared with the number of topics that patients requested. Overall staff acceptability of the transition activity was high.

The significant increase in documented transition discussions with this MA-facilitated transition activity has important clinical implications. Studies have found that transition discussions are possibly more effective when embedded into routine pediatric cardiology care, (Pastor & Elder, 2023) and taking the time to address these topics on a routine basis is a critical component of preparing patients with CHD for a successful transfer to an adult model of care (Pastor & Elder, 2023). We also found that more transition topics were documented than requested, indicating that this transition activity may have opened up the conversation as patients navigate their transition journey (Pastor & Elder, 2023). Similar to others, we found that patients prioritized asking questions about medical transition topics in our study, such as understanding their heart defects and cardiac surgeries, the names of medications and what they are used for, and future needs for cardiology visits, among others (Lopez et al., 2015).

Overall staff acceptability of the transition activity was high, and staff indicated interest in continuing this activity on an ongoing basis. Interestingly, staff scored the effectiveness of transition activities in preparing pediatric patients with CHD for transfer to adult care and its effectiveness in improving their ability to perform their usual daily clinical activities lower than

other items. However, the interpretation of what comprises 'usual daily clinical activities' could differ from staff member to staff member, based on staff roles and individual workflows.

To our knowledge, this is the first examination of an expanded role for medical assistants (MAs) in the pediatric specialty care setting. MAs have served as health coaches in the primary care setting after undergoing 40 hours of specialized training (Willard-Grace et al., 2015). No specialized training was required in this study other than what was presented at the pediatric cardiology division meeting. Additionally, MAs were provided with a prompt to introduce the study to patients. A known barrier to transition program implementation in CHD is a lack of additional staff to perform transition activities and clinic space (A.S. John et al., 2022). This MA-facilitated activity may be an amenable option to improving transition discussions. We believe that the activity was simple, effective and easy to implement, and the study did not require additional clinic space. Having time to perform transition activities is also a known barrier to transition program implementation (A.S. John et al., 2022). Even though we did not collect data on the time taken to perform this activity, it should be noted that no additional clinic time was allocated during the study period, and clinical workflows were not delayed or interrupted.

Despite this study being the first to document a MA-facilitated transition activity in CHD, there are several limitations to consider. First, this study was conducted at a single center and over a short timeframe. Second, this study was designed to be process-oriented, and we did not collect patient-reported outcomes. Third, there was the possibility that study outcomes were impacted by the Hawthorne effect given that participants were aware that the study was taking place and may have influenced their behaviors to accommodate the study. Finally, the control group data was gathered from retrospective review of visits occurring two years prior. We acknowledge that there may be institutional and professional changes in awareness and of transition practices over that period. This study methodology also relies on the accuracy of historical documentation of transition conversations, but the comprehensiveness of that documentation cannot be

ascertained retrospectively. Conversations may have taken place that were simply not documented which would thereby overestimate the treatment effect. Future research should include patient transition focused outcomes, including transfer success, measures of readiness for transition, and how this activity affects patients and families. Additionally, future research should include patient (and family) perceptions of the acceptability in the activity as convergent views are more likely to support successful implementation. The role of the MA in facilitating patient education, engagement and motivation is an area that is understudied and would benefit from further research.

Conclusion

Our study highlights that having an MA-facilitated transition activity increased documentation of transition discussions in the pediatric cardiology clinic setting. Staff were accepting of and in favor of continuing this low resource transition activity. More research is needed to better understand this intervention's impact on patients with CHD's long-term transition outcomes.

CHAPTER III

Referral Order Placement Decreases Time to Transfer to Adult Congenital Heart Disease Care

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Abstract

Background: Pediatric patients with moderate and great complexity congenital heart disease (CHD) may benefit from coordinated transfer to adult congenital heart disease (ACHD) centers to reduce the risk of complications; however, there are a variety of transfer practices. We examined the impact of referral order placement at the last pediatric cardiology visit on time to transfer to an ACHD center.

Methods: We analyzed data collected from pediatric patients with moderate and great complexity CHD who were eligible to transfer to our tertiary center's accredited ACHD center. We examined transfer outcomes and time-to-transfer between those with a referral order placed at the last pediatric cardiology visit and those without using Cox proportional hazards modeling.

Results: The sample (n = 65) was 44.6% female and mean age at study start was 19.5 years (± 2.2). Referral orders were placed for 32.3% of patients at the last pediatric cardiology visit. Those who had a referral order placed at the last visit had significantly higher number of successful transfers to the ACHD center compared to those who did not (95% vs 25%, $p < 0.001$). In a Cox regression model, placement of a referral order at the last pediatric cardiology visit was associated significantly with a sooner time to transfer (HR 6.0; 95% CI 2.2 – 16.2, $p > 0.001$), adjusting for age, sex, complexity, living location, and pediatric cardiology visit location.

Conclusions: Placement of a referral order at the last pediatric cardiology visit may improve transfer occurrence and time to transfer to accredited ACHD centers.

Introduction

Current guidelines state that patients with moderate or great complexity pediatric congenital heart disease (CHD) should transfer to an accredited adult congenital heart disease (ACHD) center (Stout et al., 2019). In the United States (US), the recommended age for transfer to an accredited ACHD center is 18-21 years of age (White et al., 2018). These years, however, are a vulnerable time for patients with CHD who may be experiencing parallel physiological, psychological, and social changes that can potentially impact a successful transfer to accredited ACHD centers (Abda et al., 2019; DeMaso et al., 2014; Kovacs et al., 2022; Moons, Skogby, et al., 2021). Patients with CHD who experience fragmentation of care during the transition years have an increased risk for developing complications leading to hospitalization and procedural intervention (de Bono & Freeman, 2005; Gurvitz et al., 2007; Iversen et al., 2007; Wacker et al., 2005; Yeung et al., 2008). In fact, patients who experience a lapse in care during the transition years have about 3 times greater odds of requiring urgent cardiac intervention compared to those with no lapse (Yeung et al., 2008).

Transfer rates of pediatric CHD patients to accredited ACHD centers are reported to be higher in countries with larger specialized CHD programs, closer location and affiliation between pediatric CHD and ACHD services, and programs with structured transfer processes (Vonder Muhll, 2020). In the US, between 11-39% of pediatric CHD patients transfer to ACHD centers (Bohun et al., 2016; S. S. Gaydos et al., 2020; Gerardin et al., 2019; Goossens, Fernandes, et al., 2015; Harbison et al., 2016; Kollengode et al., 2018; Norris et al., 2013; Vaikunth et al., 2018), which is considerably lower than transfer rates in Europe (Goossens et al., 2011; Skogby et al., 2020) and Canada (Mondal et al., 2020). In the US, structured transfer processes to accredited ACHD centers are less commonly used than in Europe (Hilderson et al., 2009; Thomet et al., 2021). Not surprisingly, gaps in care during the transition years are more common in the US than other countries (Moons, Skogby, et al., 2021). Additionally, almost half

of the US population lives over an hour away from tertiary centers (Saliccioli et al., 2019). Some tertiary care centers resolve this issue by providing care for patients at outreach sites, but patients cared for at pediatric CHD outreach sites that do not offer transfer support may be at increased risk of experiencing geographic disparity in healthcare access, resulting in sub-optimal transfer outcomes (Gurvitz et al., 2013; Lopez et al., 2022; Saliccioli et al., 2019). There are a variety of referral practices across clinical settings (e.g., timing of order placement), however, which may explain the low transfer rates in the U.S. Placement of a referral order at the last pediatric cardiology visit, regardless of location, may help alleviate some barriers to successful transfer. The purpose of this study is to examine time to successful transfer to an accredited ACHD center between those with a referral order placement at the last pediatric cardiology visit versus those with no and delayed referral order placement among pediatric patients with moderate or great complexity CHD. We hypothesized that placement of a referral order at the last pediatric cardiology visit would lead to higher occurrence of transfer to accredited ACHD centers and sooner time to transfer to an accredited ACHD center.

Methods

Study Design

In June 2022, we performed a retrospective medical record review of patients with moderate and great complexity CHD who were eligible to transfer to our tertiary center's affiliated accredited ACHD center between March 2020 and March 2022. Our tertiary health care center has both pediatric CHD and accredited ACHD facilities and is the only accredited ACHD center in the state. However, the tertiary health care center is located at the northwestern corner of the state, creating difficult access for those living in remote areas (Figure 1). Thus, patients with pediatric CHD are cared for at either the tertiary care center or at one of 11 outreach sites located across Oregon, which are staffed by pediatric cardiologists affiliated with the tertiary care center. The recommended age of transfer to our affiliated ACHD center at our institution is

age 18, although the guideline recommends that optimal timing should be considered on an individual basis from a patient and family perspective. Although, similar to other institutions, at our institution there is practice variation amongst pediatric cardiologist about preferred age and method of transfer: patients may be provided with a referral order, they may receive a telephone number to schedule an appointment with an ACHD provider, or they may be retained in pediatric cardiology care. Patients were included in the analysis if they were under the care of a pediatric cardiologist (either at the tertiary care center or an outreach center), had a primary diagnosis of moderate or great complexity CHD (Supplement 1), were 17 years or older as of March 1, 2020 and had seen a pediatric cardiologist between January 2016 and March 2022. Patients with a history of heart transplant were excluded from this analysis. The study participants were divided into two groups: 1) patients who received referral order placement to the accredited ACHD center at the last pediatric cardiology visit and 2) patients who received no referral orders at the last pediatric cardiology visit (such as those who received contact information of an ACHD center to schedule the transfer appointment themselves, or those who had no documented transfer plan), or received a delayed referral order more than thirty days after the last pediatric cardiology visit. The study was approved by the Institutional Review Board.

Data Collection

We collected baseline data from the last pediatric cardiology office visit, including sociodemographic variables (age, sex, language, insurance provider, last pediatric cardiology visit location and residence either within or outside the metropolitan area) and clinical variables (primary cardiac diagnosis, date of the last pediatric cardiology visit, date of the first ACHD center visit). We then grouped patients' cardiac anatomy by the 2018 American Heart Association (AHA) / American College of Cardiology (ACC) guideline for the management of adults with CHD ACHD Anatomic and Physiological (AP) classification system. The AHA/ACC

2018 guidelines define moderate complexity CHD as non-cyanotic defects that are either repaired or unrepaired and moderate in nature such as atrio-ventricular septal defects, repaired tetralogy of Fallot. Great complexity CHD anatomy is defined as cyanotic defects which are unrepaired or palliated and single ventricle, such a hypoplastic left heart, and transposition of the great arteries (Stout et al., 2019). (Supplemental table 1).

Then we followed up with patients to collect transfer outcomes. Patients were categorized as either 1) successful transfer (i.e., completed an initial visit with an ACHD provider), or 2) unsuccessful transfer (i.e., did not complete an initial visit with an ACHD provider). We further categorized unsuccessful transfer as either 1) Retained in pediatric care (i.e. planned continuation of pediatric cardiology care during the study period), 2) Overdue for transfer (i.e. past the due date to see an ACHD provider and not meeting criteria for being LTFU), or 3) LTFU (i.e. absent from care beyond six-months of the planned transfer date and were issued two phone calls and a letter from the ACHD team, or those who had a three-year gap in pediatric CHD care (S. S. Gaydos et al., 2020; Kollengode et al., 2018; Moons, Skogby, et al., 2021).

Data analysis

Standard descriptive statistics of frequency, central tendency, and dispersion were used to describe the sample. Comparative statistics (chi-square test, Fisher's exact test and Student's T test) were used to compare differences in sociodemographic and clinical variables between those who received referral order placement at the last pediatric cardiology visit versus those who did not. We generated time-to-transfer curves using Kaplan-Meier graphs and used the log-rank Mantel-cox test to compare the probability of successful transfer between those who received referral order placement at the last pediatric cardiology visits versus those who did not. We also explored whether CHD complexity, location of last pediatric cardiology visit, living location within or outside of the metro area, age and sex impacted time to transfer. Cox proportional hazard regression modeling was used to analyze time to transfer, adjusting for

factors significant in bivariate testing as well as age and sex. Predictors are reported as hazard ratios (HR) with corresponding 95% confidence intervals (CI). Stata/MP version 17 (StataCorp, College Station, TX) and SPSS version 28 (IBM, Armonk, NY) were used for data analysis.

Results

A total of 65 patients met inclusion and exclusion criteria. About half were female, and the majority were Non-Hispanic White (Table 1). In this sample, 21 (32.3%) patients received a referral order at the last pediatric cardiology visit. Of those who did not receive an order at the last visit, 11 (16.9%) had an order placed more than 30 days later. Significantly more patients received a referral order placement at the last pediatric cardiology visit at the tertiary care center (30.8%) compared with outreach sites (1.5%), $p > 0.001$. In this sample, 47.7% successfully transferred to the accredited ACHD center, and those with a referral order at the last visit had more successful transfers than those who did not ($p < 0.001$).

Table 1
Socio-demographics, Clinical Characteristics, and Transfer Outcomes

		Total (n = 65)	Referral order placed at last visit (n = 21)	No referral order placed at last visit (n = 44)	p-value
Socio-Demographics					
Age at Study Start (mean +/- SD)		19.49 (\pm 2.21)	19.4 (1.65)	19.53 (2.45)	0.162
Sex	Female	29 (44.6%)	12 (57.1%)	17 (38.6%)	0.190
Language	English	61 (93.8%)	19 (90.5%)	42 (95.5%)	0.589
Payer	Private	37 (56.9%)	12 (57.1%)	25 (56.8%)	1.000
Living Inside the Metro Area		14 (21.5%)	7 (33.3%)	7 (15.9%)	0.195
Clinical Characteristics					
Visit Location	Tertiary Care Center	39 (60%)	20 (95.2%)	19 (43.2%)	<0.001
CHD Complexity	Moderate Complexity CHD [†]	43 (66.2%)	12 (57.1%)	31 (70.5%)	0.401
	Great Complexity CHD ^{††}	22 (33.8%)	9 (42.9%)	13 (29.5%)	
Transfer Outcomes					
Successful Transfer	Transfer to ACHD	31 (47.7%)	20 (95.2%)	11 (25%)	<0.001
Unsuccessful Transfer	Retained in Pediatric Care	20 (30.8%)	0	20 (45.5%)	

		Total (n = 65)	Referral order placed at last visit (n = 21)	No referral order placed at last visit (n = 44)	p-value
	Overdue for Transfer	3 (4.6%)	0	3 (6.8%)	
	LTFU	11 (16.9%)	1 (4.8%)	10 (22.7%)	

† Moderate complexity CHD included: atrioventricular canal, ostium primum and tetralogy of Fallot.

†† Great complexity CHD included: congenital atresia of pulmonary valve, congenital tricuspid atresia, double inlet left ventricle, double outlet right ventricle, hypoplastic left heart syndrome, interruption of aortic arch, and transposition of great vessels

There was a significant difference in the time to transfer to the accredited ACHD center between those who received a referral order at the last pediatric cardiology visit compared with those who did not (log-rank 38.84, $p > 0.001$; Figure 2). The median time to transfer was 12.8 months (Interquartile range: 9 - 18.9) for those with a referral order placement at the last pediatric visit and 28.4 months (Interquartile range: 18 - 41.73) for those without. We also observed significant differences in time to transfer between those who were seen at the tertiary care center versus those seen at outreach sites (log-rank 8.52, $p = 0.004$), those living inside the metro area compared with those lived outside of the metro area (log-rank 4.54, $p = 0.033$), and those with greater complexity CHD versus those with moderate complexity CHD (log-rank 5.87, $p = 0.015$); these variables were then moved into the multivariate regression model also accounting for sex and age.

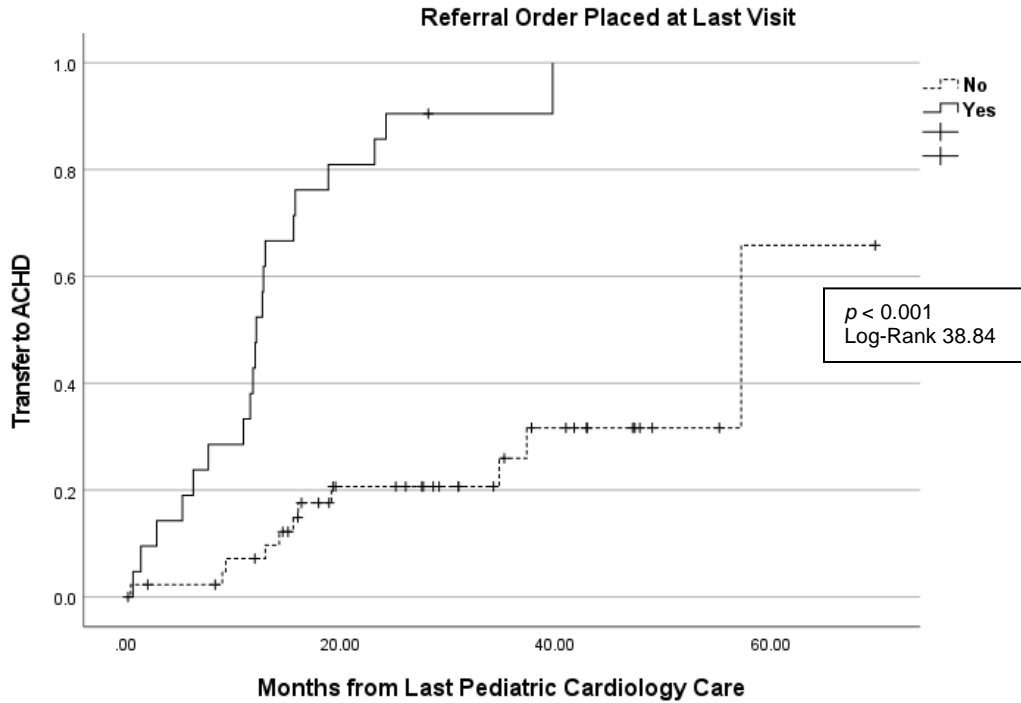


Figure 3

Time to transfer between those with referral order placement at the last pediatric cardiology visit and those who received a referral order later or not at all.

In the multivariate Cox regression model (Table 2), those with a referral order placed at the last pediatric cardiology visit were significantly more like to transfer sooner than those without (HR 6.0; 95% CI 2.2 – 16.2, $p > 0.001$), adjusting for age, sex, CHD clinic site location, living location, and CHD complexity. Older age was also significantly associated with a sooner time to transfer (Table 2).

Table 2

Cox Proportional Hazard Regression for Occurrence of Transfer to the Accredited ACHD Center

Variables	Multivariate		
	HR	(95%CI)	<i>p</i>
Referral Order at Last Visit	5.97	(2.20 – 16.21)	< 0.001
Visit Department Tertiary Care Center	1.74	(0.61 – 4.93)	0.299
Living Inside Metro Area	1.56	(0.67 – 3.64)	0.302
Great Complexity CHD	2.37	(0.98 – 5.75)	0.056
Male	0.73	(0.31 – 1.69)	0.455

Age	1.24	(1.04 – 1.49)	0.020
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HR: hazard ratio, CI: confidence interval. CHD: Congenital heart disease

Discussion

In this study, we analyzed the impact of referral order placement at the last pediatric cardiology visit on transfer outcomes and time to transfer to an accredited ACHD center in a sample of 65 transition-aged patients with moderate and great complexity CHD. We found significant differences in time to transfer to the accredited ACHD center in those who received a referral order at the last pediatric cardiology visit, adjusting for other demographic and clinical variables. Patients who received a referral order at the last pediatric cardiology visit were almost six times as likely to transfer to the accredited ACHD center than those who received no or a delayed referral order.

The transfer occurrence to the accredited ACHD center in this study (44.7%) is higher than previously reported in the US (Bohun et al., 2016; S. S. Gaydos et al., 2020; Gerardin et al., 2019; Goossens, Fernandes, et al., 2015; Harbison et al., 2016; Kollengode et al., 2018; Norris et al., 2013; Vaikunth et al., 2018). In our study 17% of our sample were lost to follow-up and 5% of our sample were overdue for transfer to an ACHD center. Patients who had a referral order placed at the last pediatric cardiology visit had a lower occurrence of lost to follow-up (1.5%), compared to those with no referral order (15%). Overall, our lost to follow-up rates were lower than previously reported in meta-analysis by Moons and colleagues (2021) who found that patients with CHD who live in the US experience higher rates of discontinuity in care during the transition years compared to those in Canada and Europe. Finally, retention in pediatric cardiology care was 31% in our study. This is comparable with studies within the US which range from 21% to 69% retention in pediatric cardiology care (Bohun et al., 2016; Gerardin et al., 2019; Goossens, Fernandes, et al., 2015; Harbison et al., 2016; Kollengode et al., 2018; Norris et al., 2013). Although our institutions guidelines recommended transfer to our ACHD center at 18 years of age, we noted practice variation in cardiologist preference for transferring

patients versus retaining patients in pediatric cardiology care. Retention in pediatric cardiac care was higher at outreach sites (40%) compared to the tertiary care center (23%). This may be because providers chose to continue pediatric cardiac care versus choosing to transfer a patient to a distant site.

Our findings are in line with previous studies which have linked formal referral to ACHD centers with successful transfer outcomes (Bohun et al., 2016; Reid et al., 2004), and extends these findings by identifying which part of the referral process aids successful transfer to ACHD centers. At our ACHD center, referral order placement triggers a proactive outreach by a scheduling specialist, and it seems to be most effective when the referral order placement is done concurrently with the last pediatric cardiology visit. These contextual factors may explain the mechanism by which referral order placement facilitates sooner time to transfer.

Distance to the referral center has shown to either have no effect on transfer outcomes (Bohun et al., 2016; Goossens, Fernandes, et al., 2015; Goossens et al., 2011; Harbison et al., 2016) or to negatively impact transfer outcomes (Gerardin et al., 2019; Mondal et al., 2020; Reid et al., 2004). In this study, living inside the metro area seemed to shorten the time to transfer to the accredited ACHD center, but not when other variables were adjusted for in the model. Given that many patients with CHD live far away from ACHD centers, referral order placement may be one possible way to reduce geographic disparities.

In our study, the median time to transfer to the accredited ACHD center with referral order placement at the last visit was just under 13 months. This time frame is comparable to a study including a similar cohort of patients who underwent a robust resource-intensive transition program intervention in Texas (mean time to transfer was 13 months) (Hergenroeder et al., 2018). Comparing the two studies, our patients, who received a referral order alone, waited a similar amount of time to transfer to an ACHD center as the more intensive intervention. Thus,

the simple placement of a referral order may demonstrate successful outcomes on par with more intensive interventions.

In clinical practice, placement of a referral order at the last pediatric cardiology visit may not require resource intensive processes. As placement of a referral order may lead to successful transfer outcomes and shorter time to transfer to accredited ACHD centers, it should be considered as a component of routine transfer of care practices. Providing clinicians with education about the downstream impact of the cascade of events that are triggered by a referral order placement as well as creating standard processes around referral order placement may help drive this practice.

Limitations of this study include the small sample size, a racially homogenous sample, a single site academic center and limitations based on retrospective record review. We did not collect data on patient and parent readiness for transfer, social, environmental, and structural factors related to race and racism, or other socioeconomic barriers impacting care (e.g., access to transportation), due to limitations of retrospective record review. This study requires validation from larger samples that are representative of the broader US population. Also, there is a need for a better understanding of the barriers of implementing structured transfer processes in the US, which are more common in other countries. Lastly there is a need to design interventions to improve the transfer process.

Conclusion

Our study highlights that referral order placement at the last pediatric cardiology visit improves transfer outcomes and time to transfer to accredited ACHD centers from pediatric CHD centers. These findings are important as CHD patients who experience lapses in care during the transition years are at risk for developing complications.

Supplement 1

Supplement 1: Number (percent) of patients with moderate and great complexity congenital heart disease (CHD).

CHD Anatomy	Diagnosis	Total (n = 65)	Referral order placed at last visit (n = 21)	No referral order placed at last visit (n = 44)
Moderate Complexity	Endocardial cushion defect/ atrioventricular septal defect	20 (30.8%)	3 (14.3%)	17 (38.6%)
	Ostium Primum	3 (4.6%)	0	3 (6.8%)
	Tetralogy of Fallot	20 (30.8%)	9 (42.9%)	11 (25%)
Great Complexity	Congenital Atresia of Pulmonary Valve	2 (3.1%)	1 (4.8%)	1 (2.3%)
	Congenital Tricuspid Atresia	3 (4.6%)	2 (9.5%)	1 (2.3%)
	Double Inlet Left Ventricle	2 (3.1%)	0	2 (4.5%)
	Double outlet right ventricle	3 (4.6%)	2 (9.5%)	1 (2.3%)
	Hypoplastic left heart	5 (7.7%)	1 (4.8%)	4 (9.1%)
	Interruption of Aortic Arch	1 (1.5%)	1 (4.8%)	0
	Transposition of the great arteries	6 (9.2%)	2 (9.5%)	4 (9.1%)

CHAPTER IV

Congenital Heart Disease Transition Practices in the United States: A survey of adult congenital heart disease programs

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This manuscript is presented to the Oregon Health & Science University School of Nursing in partial requirement of the degree of Doctor of Philosophy. This manuscript represents a significant contribution to the Dissertation work. The proposed target journal for this manuscript is Congenital Heart Disease/JACC: Advances, a peer reviewed journal that publishes articles on

advances in pediatric and adult congenital heart disease research in the US and focuses on a clinical audience; has no Impact Factor as yet.

Abstract

Background: International organizations recommend that patients with congenital heart disease (CHD) should undergo a structured transition process to prepare for lifelong cardiac care. It is not clear what transition practices are currently in place for patients with CHD at adult CHD (ACHD) programs in the United States (US) and if that support varies by location of pediatric cardiology and adult ACHD clinics.

Method: We conducted a descriptive, cross-sectional survey of ACHD programs in the US. The survey included questions about the ACHD program and patient population, transition practices (preparation, transfer, and integration), outreach sites and private practice, as well as an opportunity to describe barriers. Programs were categorized as either co-locating or not co-locating. Descriptive and comparative statistics were used to describe the state of transition practices in the U.S. overall and by location of pediatric cardiology and adult ACHD clinics.

Results: We received responses from 37 ACHD programs (36% response rate). Around 70% of responding ACHD programs reported formal transition programs as well as having a transfer process to receive patients from pediatric cardiology. Physicians were the most commonly reported transition specialists. Few programs reported having psychologists or psychiatrists on their teams or offered support for patients with developmental delay. The main barriers affecting transition were insurance and health care costs. There were no significant differences in transition practices between location groups.

Conclusion: Over two-thirds of respondent ACHD programs reported the presence of formal transition programs. More support staff are needed within these programs to meet international recommendations, to address patient psychological well-being, barriers related to insurance and health care costs. Processes are needed to support patients with developmental delay.

Introduction

International organizations recommend that patients with congenital heart disease (CHD) undergo a structured transition process to prepare for lifelong cardiac care (A. S. John et al., 2022; Moons, Bratt, et al., 2021). Transition is the process of moving from a pediatric model of health care to an adult model of health care, beginning at around 12-13 years of age and continuing until successful integration into adult congenital heart disease (ACHD) care (A.S. John et al., 2022; Stout et al., 2019; White et al., 2018). A formal transition program provides opportunities for youth to increase their knowledge about their condition, increase self-management and advocacy skills, be prepared for the differences between pediatric and adult models of care, and experience a coordinated transfer process and integration into ACHD programs (A.S. John et al., 2022; White et al., 2018). Studies show that CHD transition programs play a role in decreasing gaps in care during the transition years (Moons, Skogby, et al., 2021), decreasing time to transfer to ACHD programs (Hergenroeder et al., 2018; Mackie et al., 2018), and limiting deterioration in New York Heart Association Functional Classification scores during the transfer period (Hergenroeder et al., 2018). Studies have also shown increased patient empowerment (E. L. Bratt et al., 2023), cardiac knowledge (E. L. Bratt et al., 2023; Goossens, Fieuws, et al., 2015; Goossens et al., 2014; Ladouceur et al., 2017; Mackie et al., 2014; Mackie et al., 2022; Mackie et al., 2018), readiness for transfer (Mackie et al., 2018; K. Uzark et al., 2019), and self-management skills (Mackie et al., 2014; Mackie et al., 2022).

The presence of transition programs in pediatric cardiology in the United States (US) are more commonplace today than at the turn of the century (Basile et al., 2023; Hilderson et al., 2009). It is not clear, however, what type of transition support emerging adults with CHD are currently receiving within ACHD programs, and if this support meets international recommendations (A.S. John et al., 2022; Moons, Bratt, et al., 2021). International recommendations include guidance on necessary steps to take to complete the transition process (Moons, Bratt, et al., 2021) while

considering social determinants of health (SDOH), psychosocial well-being, and neurocognitive status of patients within the transition process (A.S. John et al., 2022). Given healthcare system differences across countries, it is important to understand how these recommendations are being implemented in different countries. It is also unknown if the location proximity of a pediatric CHD clinic and an ACHD clinic (i.e., clinics are co-located or not) influences transition practices, which may be a modifiable target for future intervention. By having a better understanding of transition practices offered by ACHD programs in the US, we will have a benchmark of current transition practices, including if practices meet international recommendations, and we generate amenable targets for intervention to optimize transition practices across settings. The aim of this study was to characterize ACHD transition practices across the US and to identify how these practices vary between pediatric cardiology and ACHD clinic location.

Methods

We developed a survey (Supplemental Table 1) based on a questionnaire distributed previously in Europe (Thomet et al., 2021). The content, face validity, and feasibility of the previously employed survey are reported by Hilderson and colleagues (2009). We captured questions from the survey related to the ACHD program structure, ACHD program staff, formal transition program, and structured transfer. We then adapted questions to the US context (Supplemental Table 2). The survey underwent review by five experts in the field and a thorough review and revision by three experts in the field, including a CHD transition program director, an ACHD transition program director, and an ACHD Nurse-Practitioner (NP). The final survey included a total of 50 questions centered on the ACHD program and patient population (12 questions), transition activities (13 questions), transfer activities (11 questions), integration activities (5 questions), outreach sites and private practice (5 questions), as well as an opportunity to

describe barriers. The Oregon Health & Science University Institutional Review Board approved this study.

Procedures

We identified ACHD programs through the Adult Congenital Heart Association (ACHA) clinical directory. The directory listed 109 ACHD programs in the US and 210 satellite sites. Email addresses of ACHD directors and staff were identified for 103 (95%) of these programs. The first round of surveys was emailed in June 2023 using the Qualtrics platform (Qualtrics, Provo, UT), and weekly reminders were sent thereafter for four weeks. The survey was also distributed via the "PediHeartNet" email list-serve of pediatric and ACHD cardiologists, and the survey received a mention in the July (2023) Adult Congenital Heart Association (ACHA) newsletter. The program's/center's clinical director, administrative director, or any ACHD staff member was asked to complete the survey. All data and results were self-reported by each center. If two or more surveys were returned from the same program, we included the survey with the most number of completed questions. We removed data that could identify an ACHD program.

Location between Pediatric Cardiology and ACHD Clinics

Programs were grouped based on location characteristics: 1) ACHD clinics co-located with pediatric cardiology clinics (i.e., share the same clinic space), 2) ACHD clinics located separately from pediatric cardiology clinics but within the same health care system, and 3) ACHD clinics housed within a different health care system from the pediatric cardiology clinic.

Statistical Analysis

Descriptive statistics, including measures of central tendency and dispersion were used to describe the sample. Hedge's g was used to measure effect sizes when measuring mean differences between program structures using independent samples t-tests. SPSS version 28 (IBM, Armonk, NY) was used for data analysis.

Results

A total of 42 out of 103 surveys (41%) were returned. After four duplicate sites were removed, 38 (37%) surveys were included in the final analysis. In an examination of practice location between ACHD clinics and the pediatric cardiology clinics from where the majority of patients were referred, 24 programs (63%) shared a co located clinic space, 13 programs (34%) were located in a separate space in same health care system and one (3%) program received the majority of their pediatric cardiology patients from a different system. This program was excluded from the final analysis given the small number and concerns for protecting identity. Thus, a total of 37 (36%) of respondents were included in the analysis.

Program Characteristics

We received survey responses from ACHD programs in 25 states located across the mainland US. Of the 37 ACHD program survey responses, two-thirds of programs reported being accredited by the Adult Congenital Heart Association (Table 1). Over half of the ACHD programs reported being located in a metro area with a population of > 1.5 million people. Survey participants estimated that around half of patients who receive care at their ACHD program are insured publicly (such as Medicaid, Medicare, or state sponsored plans) and 80% are from English-speaking families. The number of years that the ACHD programs have been in place ranged from 2 - 42 years with a median of 13 years (IQR 6-18). We also stratified pediatric cardiology and ACHD programs by location and found no meaningful difference in effect size (data not shown).

Table 1
ACHD Program Characteristics

	Total n = 37
ACHD program accredited	25 (67.6%)
Approximate size of the metro area >1.5 million	20 (55.6%)
750 000 - 1.5 million	5 (13.9%)

250 000 – 749 999	8 (22.2%)
<250 000	3 (8.3%)
Proportion of patients with public health insurance. Mean% (SD)	49.56% (\pm 22.88);
Proportion of patients that are English speaking Mean% (SD)	80% (\pm 19.65)

Abbreviations: SD, standard deviation.

Transition Program Staffing, Models and Practices

Formal transition programs reported having between two to seven transition specialists on a team (median 4, IQR [3-5]). Physicians were the most commonly reported transition specialists. Few programs reported having psychiatrists (3%) and psychologists (11%) on staff (Figure 1). The most frequently reported transition program models were NP/physician assistant (PA)-led clinic-based (30%), and pediatric cardiologist-led clinic-based (30%), followed by registered nurse (RN)-led clinic-based (27%) (Table 2).

Table 2
Transition Programs, Models and Practices

	Total n = 37
Formalized transition program	25 (67.6%)
Institutional transition policy in place	23 (62.2%)
Transition program model:	
RN - led clinic-based	10 (27%)
NP/PA - led clinic-based	11 (29.7%)
SW-led clinic based	4 (10.8%)
Pediatric cardiologist-led clinic based	11 (29.7%)
RN - led virtual	5 (13.5%)
NP/PA - led virtual	4 (10.8%)
SW - led virtual	1 (2.7%)
Pediatric cardiologist- led virtual	6 (16.2%)
Multidisciplinary clinic	3 (8.1%)
Other	1 (2.7%)
Transition practices offered:	
Group sessions	2 (5.4%)
One time transition counseling partnered with same day clinic visits	10 (27%)
Serial transition counseling partnered with same day clinic visits	14 (37.9%)
One-to-one counseling not partnered with same day clinic visits (happen on separate days)	16 (43.2%)
Online transition preparatory module	3 (8.1%)
Handout with links and resources	18 (48.7%)

Referral to an outside transition focused clinic	1 (2.7%)
Transition tools used:	
Transition Readiness Assessment	24 (64.9%)
Measures of congenital heart disease knowledge	17 (46%)
Measures of health literacy	14 (37.9%)
Measures of health-related quality of life	7 (18.9%)
Measures of self-efficacy and independence	13 (35.1%)
Other	2 (5.4%)
Different processes in place to support transition of patients with developmental delay	8 (21.6%)

The most frequently reported transition practices offered by programs were handouts with links and resources (49%), followed by one-to-one counseling separate from clinic visits (43%).

Transition readiness assessments were the most frequently reported assessment tools (65%), followed by measures of congenital heart disease knowledge (46%). Most programs reported delivering these transition practices at least once after transfer to their ACHD program (24%), and few programs reported delivering five or more transition practices. Fewer programs reported having a transition process for patients with developmental delay (22%).

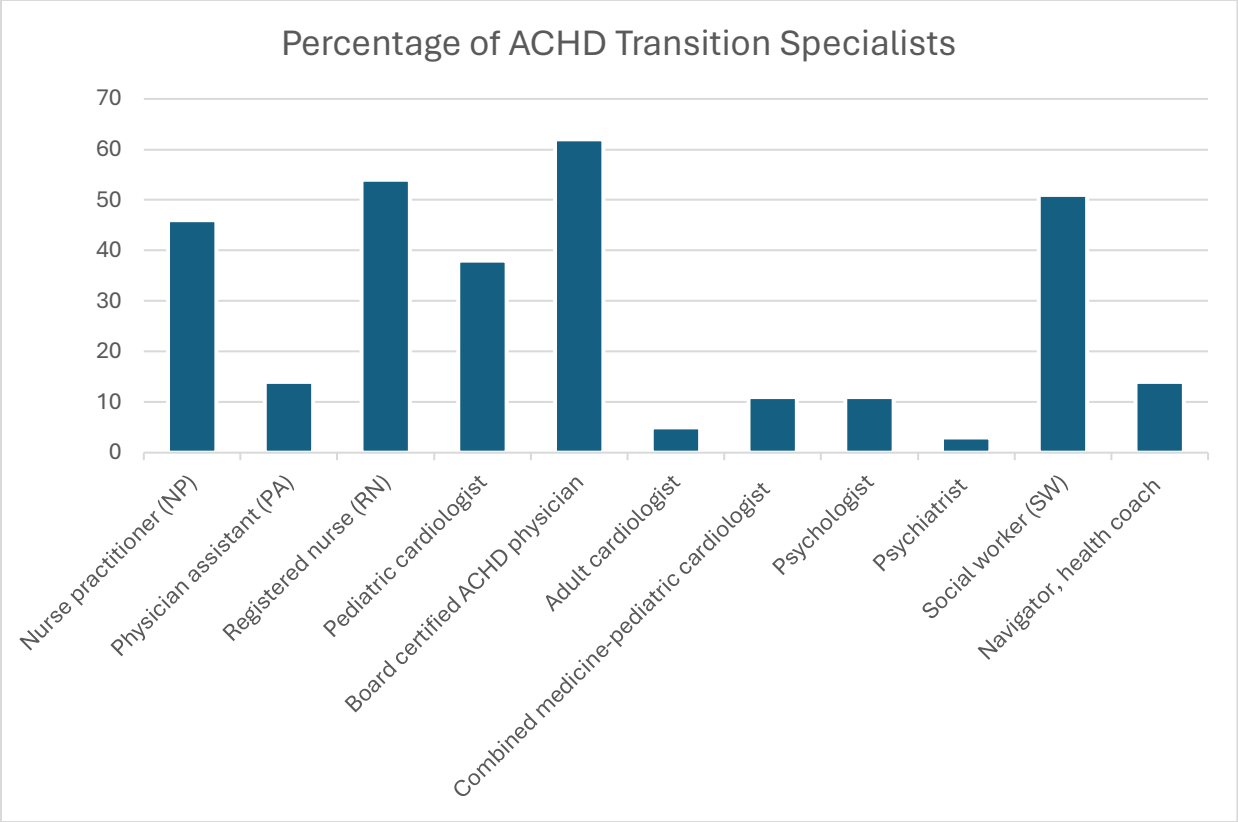


Figure 1.
Percentage of ACHD Program Transition Specialists

Preparation, Transfer, and Integration

ACHD program respondents perceived that most patients received some transition preparation from the pediatric cardiology program prior to transfer, but preparation was lowest when patients were transferred from private practice pediatric cardiology (Table 3). Over two-thirds of programs reported having a transfer process from pediatric cardiology to their ACHD program. Over half of programs reported having a flexible transfer age based on development.

Table 3.
Preparation, Transfer, and Integration

Total n = 37	
Preparation	
How much transition preparation patients appear to have received prior to transfer to the ACHD program from pediatric cardiology	

None	4 (10.8%)
Some	24 (64.9%)
Enough	9 (24.3%)
Patients from pediatric cardiology outreach sites appeared to receive the same amount of transitions preparation as those from the pediatric cardiology program	15 (40.5%)
Pediatric cardiology patients from private practice appeared to receive the same amount of transition preparation as those from other health care systems	
Yes	5 (13.5%)
The ACHD program has outreach sites (i.e., clinics that are at places outside of the main ACHD campus)?	30 (81.1%)
Patients receive the same transition activities at ACHD outreach sites as those from the ACHD program	22 (59.5%)
Electronic medical record transition workflow to document and track/monitor transition activities	17 (46%)
Patients have access to their pertinent medical records via a patient portal or other means	36 (97.3%)
Multidisciplinary transition meetings to discuss high risk youth transferring from pediatric cardiology to ACHD	17 (46%)

Transfer

Transfer process from pediatric cardiology to ACHD at your institution	
Yes	26 (70.3%)
Sometimes	6 (16.2%)
Structured age at which pediatric patients are handed off to your team	
At age 18	2 (5.4%)
Between ages 18-21	14 (37.9%)
Flexible based on development	23 (62.2%)
Dependent on pediatric cardiology team	16 (43.2%)
Option for patients to visit the ACHD clinic prior to transfer	26 (70.3%)
Option for patients to meet an ACHD team member at the last pediatric cardiology clinic visit	4 (10.8%)
Pediatric cardiology team transfers CHD patients regardless of CHD complexity to the ACHD program, or only select patients	
All	24 (64.9%)
Not all	13 (35.1%)
Transfer/referral order placed	16 (43.2%)
An ACHD provider is identified during the transfer process	30 (81.1%)
A formal transfer summary is created	5 (13.5%)

Integration

Outreach by a scheduling specialist to make the patients first appointment	23 (62.2%)
Process to follow-up with patients who did not successfully transfer	16 (43.2%)
A welcome letter is sent to the patient/ family from the ACHD program	10 (27%)
A process to track 'no show' patients to call them and reschedule the appointment	33 (89.2%)
Patients are sent text messaging reminders	28 (75.7%)
A process to measure how many patients keep their second follow-up in the ACHD clinic	8 (21.6%)
A process to follow-up with patients who are overdue for care	20 (54.1%)

The majority of programs reported that patients had an option to visit the ACHD clinic prior to transfer but few programs reported that patients had an option to meet with an ACHD team member prior to transfer. Around two-thirds of respondents reported that the pediatric cardiology program from where they receive the majority of their patients transferred all patients with CHD to their program, regardless of CHD complexity. Perceived reasons for not receiving all patients with CHD from pediatric cardiology included: retention in pediatric cardiology care (until after college, until they are considered too old for pediatric cardiology, or per patient request). Some perceived that patients are more likely to be transferred during an event (such as pregnancy), and others perceived patients moved to other locations, or were transferred to another specialty. Almost all (89%) programs reported having a process to track and reschedule patients that did not arrive at their scheduled appointment and just over half of programs reported a process to follow-up on patients who are overdue for care. The most frequently reported metric to measure transition program success was successful transfer to ACHD care (32%) (Table 4). The barriers perceived to successful transfer to ACHD programs were mostly related to insurance barriers and the cost of health care.

Table 4.
Formal Metrics

	Total n = 37
Formal metrics measuring success of the transition program	
Score improvement on transition survey tools	5 (13.5%)
Expected progression of knowledge and skills	7 (18.9%)
Successful transfer to ACHD	12 (32.4%)

Discussion

In this study we present data regarding current CHD transition practices in the US from the perspective of 37 ACHD programs located across the US mainland, which ranged from newly formed programs to those spanning four decades in program length. We found that two-thirds of the programs were accredited by the Adult Congenital Heart Association and had formal

transition programs in place. Over two-thirds of programs reported having a transfer process from pediatric cardiology to their ACHD program. Physicians were the most commonly reported transition specialists. Few programs reported having psychologists and psychiatrists on staff to address patient psychosocial well-being and few programs reported having processes in place to support those with developmental delay. From these findings we have a benchmark for current transition practices offered by ACHD programs in the US, including in comparison with our European colleagues and whether these transition practices meet international recommendations.

Transition Comparison with European Colleagues

Transition practices vary internationally. In a 2017 survey of 96 ACHD programs in Europe, the presence of formal transition programs was reported to be at 41.7% (Thomet et al., 2021) and in a 2019 survey of 48 pediatric cardiology programs in North America (US and Canada), the presence of formal transition programs was reported to be at 71% (Basile et al., 2023). In our survey, the presence of transition programs at surveyed ACHD programs in the US were similar to those reported in the pediatric cardiology programs in North America (Basile et al., 2023). Transfer, which is the movement of care from a pediatric to an adult health care professional or team, is one component of transition (A.S. John et al., 2022). International recommendations suggest that the transfer process should be structured (i.e. an active referral should be placed, and a medical summary should be provided to the ACHD team, among others) (Moons, Bratt, et al., 2021). In previous survey findings, the presence of structured transfer processes to ACHD were more common in Europe than the US (Hilderson et al., 2009). In a 2017 survey of 96 ACHD centers in Europe, structured transfer processes were reported to be 88.5% (Thomet et al., 2021). In our survey 70% of programs reported to have a transfer process. While still behind our European colleagues, these gains are encouraging. In our survey, programs tended to be in favor of a flexible transfer age, which was a similar finding in the European survey (Thomet et

al., 2021). Although in Europe, some centers transfer patients to ACHD care at around age 16 (Goossens et al., 2011), which is younger than the recommended transfer age in the US (A.S. John et al., 2022). Our findings were similar to our European colleagues in the presence of a written transition protocol, and the percentage of patients with CHD that are transferred to the ACHD program from pediatric cardiology, regardless of disease severity (Thomet et al., 2023; Thomet et al., 2021). In our survey, more patients had access to their medical records compared to the European survey, but disappointingly, few pediatric cardiology programs prepared a transfer summary for the ACHD program (Thomet et al., 2023; Thomet et al., 2021). The European survey showed that the majority of transferring youth are offered joint or overlapping appointments between the pediatric cardiology and ACHD team (Thomet et al., 2023; Thomet et al., 2021). We found the majority of programs reported that patients had an option to visit the ACHD clinic prior to transfer but few programs reported that patients had an option to meet with an ACHD team member in the pediatric cardiology clinic prior to transfer.

Transition Program Staff

In our survey, ACHD transition programs reported a higher number of specialists on a team than our European colleagues (Thomet et al., 2021). However, this comparison should be interpreted with caution as the European survey explored dedicated hours allotted to transition. We did not explore dedicated hours allotted to transition because we felt that these hours would be difficult to identify as transition activities tend to be incorporated with routine care in the US. This is an area of opportunity for future research. Our European colleagues reported that more than half of transition programs had multidisciplinary team members consisting of NPs, physicians, psychologists and/or social workers (SWs) (Thomet et al., 2021). In our survey we noted that few programs reported the presence of a psychiatrist or psychologist on the transition team. This is concerning as psychiatric disorders are the most common comorbidity experienced by patients with CHD, and there is strong need to integrate mental health professionals into CHD

care (Kovacs et al., 2022; Miles et al., 2023). We also noted that only half of respondents reported that their ACHD program had a SW on their transition team. SWs play a key role in assessing the need for mental health resources as well as resources to aid in the successful continuity of care, such as maintaining health insurance (A.S. John et al., 2022). Given that the most commonly reported barriers are related to insurance/cost of healthcare, the underutilization of SWs may exacerbate this situation.

Transition Program Practices

Similar to others, the most commonly utilized transition tools were measures of cardiac knowledge (E. L. Bratt et al., 2023; Goossens, Fieuws, et al., 2015; Goossens et al., 2014; Ladouceur et al., 2017; Mackie et al., 2014; Mackie et al., 2022; Mackie et al., 2018) and measures of readiness for transfer (Mackie et al., 2018; K. Uzark et al., 2019). Programs reported a variety of transition practices, which is similar to the European survey (Thomet et al., 2021). The most commonly reported transition practice in our survey were handouts with links and resources. In our survey the majority of respondents perceived those patients transferred from pediatric cardiology received some transition preparation prior to transfer to the ACHD program. Patients who do not receive adequate preparation may experience gaps in care placing them at risk for complications requiring more frequent visits to the emergency department, hospitalization and procedural intervention (de Bono & Freeman, 2005; Gurvitz et al., 2007; Iversen et al., 2007; Wacker et al., 2005; Yeung et al., 2008). We did not examine pediatric cardiology transition practices in this survey, which is an area of opportunity for future research, although just under a third of programs reported having formal metrics in place to measure successful transfer to ACHD. Placement of a referral/transfer order by the pediatric cardiology team is associated with a decreased time to transfer to ACHD (Burger et al., 2023). In our survey referral orders were perceived to take place prior to transfer by under half of respondents. Almost all programs reported having a process to track and reschedule patients

who did not arrive at their scheduled appointment with ACHD and just over half of programs reported having a follow-up process in place for patients who are overdue for ACHD care.

Transition Support

Communication between the patient, pediatric cardiology, and ACHD team members is essential for promoting continuity in care among patients who are transitioning to ACHD programs (A.S. John et al., 2022). Overall, in our survey many programs reported robust communication methods between the ACHD team and patients, such as sending welcome letters to patients who are transferring to ACHD care and offering outreach by a scheduling specialist for patients to make their first appointment. Text message reminders were frequently reported methods of communication, as well as patient portal access. Communication methods between healthcare teams (pediatric cardiology and the ACHD program) appeared to be less commonplace, such as the presence of multidisciplinary transition meetings to discuss high risk youth transferring from pediatric cardiology to ACHD and the presence of a transfer summary from pediatric cardiology, suggesting an area of future research opportunity. Lastly, international recommendations suggest consideration for the needs of patients with developmental delay, such as establishing medical power of attorney for those with severe developmental delay or a shared decision-making pathway for those with less severe developmental delay (A.S. John et al., 2022). Few respondents reported having a process to support transition patients with developmental delay in our survey.

Strengths and limitations

Strengths of this study included survey input from transition experts and survey responses from across the mainland US. Study limitations included a 36% response rate, difficulty locating contact details of ACHD programs listed in the ACHA registry, as well as locating programs that are not listed in the registry. We attempted to overcome these limitations by ensuring the survey was well-designed, tested on experts in the field, and we incorporated multiple recruitment

methods, such as placing the survey on the "PediHeartNet" group, and the July (2023) ACHA newsletter (Shiyab et al., 2023). We also attempted to add a personalized touch to the survey with an opening 'Greetings from the Northwest (Shiyab et al., 2023).' Our data were also limited by self-reports and possible response bias. It could be likely that centers that are doing transition well were more willing to respond than those that are not. Lastly, we did not receive sufficient responses from programs that were located separately and not within the same institution, limiting our ability to benchmark transition activities across all ACHD settings. Pediatric cardiology perspectives were not examined in this survey and therefore more research is needed to examine current pediatric cardiology transition practices.

Conclusion

Over two-thirds of ACHD programs surveyed reported the presence of formal transition practices. More support staff are needed to expand transition practices beyond patient handouts, to address patient psychological well-being, barriers related to insurance and health care costs, and to support patients with developmental delay. More research is needed to fully understand and address current gaps in meeting international transition recommendations, such as learning more about transition staffing practices and resources in ACHD programs in the US and gaining transition perspectives from pediatric cardiology programs. Lastly, more work is needed to increase communication between pediatric cardiology and ACHD programs, such as multidisciplinary meetings to discuss high risk transferring youth and transfer summaries.

Supplement 1

Survey Questions

Institution and patient population		
1. Name of hospital.		
2. Name of adult congenital heart disease (ACHD) program.		

3. Director of the ACHD program.		
4. By your best recollection what year was your ACHD program established?	_____	
5. Is your ACHD program accredited?	Yes	No Unsure
6. (If yes to above) Is your program accredited by the Adult Congenital Heart Association?	Yes	No Unsure Other _____
7. From where are pediatric cardiology patients transferred to your program? (select multiple).	pediatric private practice Same health care system Other health care system (s) Unsure	Other _____
8. <i>Based on the program from where the majority of your patients with CHD are transferred: is your ACHD program co-located in the same health care system with a pediatric cardiology program?</i>	Yes Unsure	No
If yes to above): Do they share the same clinic space?	Yes Unsure	No
(If no to above) Is your ACHD program located within the same health care system on the same campus but in a separate building from the pediatric cardiology program?	Yes Unsure	No
(If no to above): Is your ACHD program located within the same health care system but on a different campus or located separately from the local pediatric cardiology program(s)?	es Unsure	No
(If no to above) Is your ACHD program located in a different health care system and separate from the pediatric cardiology program(s)?	Yes Unsure	No

<p>9. What is the distance between your ACHD and the pediatric cardiology program (from where the majority of your patients with CHD are transferred)?</p>	<p>1-5 miles 6-10 miles 1-15 miles 16-20 miles > 20 miles Various distances N/A: same campus or clinic Unsure</p>	
<p>10. What is the approximate size of the metro area where your ACHD program is located? A population of:</p>	<p>> 1.5 million 750 000 – 1.5 million 250 000 – 749 999 < 250 000</p>	
<p>11. What proportion of your population has public health insurance (such as Medicaid, Medicare, or State sponsored plans)? (Best estimate. Skip to the next question if unsure).</p>	<p>Percent bar in Qualtrics from 0-100</p>	
<p>12. What proportion of your families are English speaking? (Best estimate. Skip to the next question if unsure).</p>	<p>Percent bar in Qualtrics from 0-100</p>	
<p style="text-align: center;">Transition facility and staff</p> <p>Definition: Formalized congenital heart disease transition program: “Improving patient knowledge, self-management, and self-efficacy skills to the level they are capable to eventually integrate smoothly into adult-oriented health care.”</p> <p>John, A. S., Jackson, J. L., Moons, P., Uzark, K., Mackie, A. S., Timmins, S., ... & Gurvitz, M. (2022). Advances in managing transition to adulthood for adolescents with congenital heart disease: a practical approach to transition program design: a scientific statement from the American Heart Association. Journal of the American Heart Association, 11(7), e025278</p>		
<p>13. Do you have a formalized transition program for patients with CHD according to the definition above?</p>	<p>Yes</p>	<p>No Unsure .</p>
<p>14. Does your ACHD program have a written protocol to guide transition activities?</p>	<p>Yes</p>	<p>No Unsure</p>
<p>15. What roles are represented in delivering core transition services as</p>	<p>Nurse practitioner, physician assistant, registered nurse, pediatric cardiologist, board certified ACHD physician, adult cardiologist, combined medicine-pediatric cardiologist, Internal medicine physician, psychologist, psychiatrist, social</p>	

part of your formalized program (multiple responses possible).	worker (LCSW or MSW), a “health coach” or “transition navigator” or a “health care navigator” or no transition specialists in our formal transition program	
Clinical preparation activities		
16. What kinds of transition activities does your ACHD program offer? (Multiple responses possible).	Group sessions One time transition counseling partnered with same day clinic visits Serial transition counseling partnered with same day clinic visits One-to-one counseling not partnered with same day clinic visits (happen on separate days)	Online transition preparatory module Handout with links and resources Referral to an outside transition focused clinic
17. What transition model does your ACHD program use? (Multiple responses possible).	Nurse - led clinic-based NP/PA - led clinic-based Pharmacist- led clinic based SW - led clinic based (LCSW or MSW) Pediatric cardiologist- led clinic based Nurse - led virtual NP/PA - led virtual Pharmacist - led virtual SW - led virtual (LCSW or MSW) Pediatric cardiologist- led virtual Other _____ Unsure	Multi-disciplinary transition clinic
18. Which of the following transition tools does your ACHD program use?	Transition Readiness Assessment _____	Measures of congenital heart disease knowledge
	Measures of health literacy	Measures of health-related quality of life __
	Other: _____ Unsure	Measures of self-efficacy and independence
19. How many transition encounters does a patient receive at your ACHD program (if applicable)?	1 2 3 4 5 or more Unsure	
20. Does your transition program have formal	Score improvement on transition survey tools	Expected progression of knowledge and skills

metrics measuring success of your transition program?	No Unsure	Successful transfer to ACHD
21. Is there a different process to support transition of patients with developmental delay at your ACHD program?	Yes	No Unsure _____
22. Is there an electronic medical record transition workflow to document and track/monitor transition activities?	Yes	No Unsure
23. Do patients at your ACHD program have access to their pertinent medical records via a patient portal or other means?	Yes	No Unsure
24. How much transition preparation do patients appear to have received prior to transfer to your ACHD program (from where the majority of your patients with CHD are transferred)?	None Some Enough Well-prepared	
25. Do you have multidisciplinary transition meetings to discuss high risk youth transferring from pediatric cardiology to your ACHD program?	Yes	No Unsure
Transfer activities		
<p>Transfer Definition: Transfer of care is "the actual point in time when a patient's care moves from a pediatric to an adult health care professional or team." John, A. S., Jackson, J. L., Moons, P., Uzark, K., Mackie, A. S., Timmins, S., ... & Gurvitz, M. (2022). Advances in managing transition to adulthood for adolescents with congenital heart disease: a practical approach to transition program design: a scientific statement from the American Heart Association. Journal of the American Heart Association, 11(7), e025278.</p>		
26. Do you have a transfer process from pediatric cardiology to ACHD at your institution according to the	Yes Unsure	No Sometimes Detail _____

definition above (from where the majority of your patients with CHD are transferred)?		
27. Is there a structured age at which pediatric patients are handed off to your team (from where the majority of your patients with CHD are transferred)?	At age 18 Between ages 18-21 Unsure	Flexible age based on development No protocol: dependent on the pediatric cardiology team
28. Please estimate the number of patients that transferred from pediatric cardiology to your ACHD program in 2022. (If unknown leave blank).	-----	
29. Is there an option for the patient to visit the ACHD clinic prior to transfer from pediatric cardiology clinic?	Yes	No Unsure
30. Is there an option for the patient to meet with an ACHD team member at the last pediatric cardiology appointment?	Yes	No Unsure
31. Does the pediatric cardiology team transfer all CHD patients who are aging into adult care to your institution or only select patients? (e.g., only complex defects)	All patients Unsure	Not all patients Detail _____
32. Is a transfer/referral order placed by the pediatric cardiology program to your ACHD program?	Yes Unsure	No
33. Is an ACHD provider identified during the transfer process by the pediatric team?	Yes Unsure	No
34. Is a formal transfer summary created during the transition process by the	Yes	No Unsure

pediatric cardiology team?		
35. Does your ACHD program offer outreach by a scheduling specialist to help patients make their first appointment? (e.g., 2 phone calls and a letter by a support staff member?)	Yes	No Unsure
36. Do you have a process to follow-up with patients who did not successfully transfer from pediatric cardiology to your ACHD program?	Yes	No Unsure
Integration Activities		
<p>Definition: Integration is the process of establishing care in an adult model of care that can fully meet a patient’s complex needs.</p> <p>Rosen, D. S., Blum, R. W., Britto, M., Sawyer, S. M., & Siegel, D. M. (2003). Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. <i>Journal of Adolescent Health, 33</i>(4), 309-311.</p>		
37. Is a welcome letter sent to the patient/ family from your ACHD program?	Yes	No Unsure
38. Does your ACHD program track ‘no show’ patients to call them and reschedule the appointment?	Yes	No Unsure
39. Are patients sent text messaging appointment reminders?	Yes	No Unsure
40. Does your ACHD program measure how many patients keep their SECOND follow up in the ACHD clinic?	Yes	No Unsure
41. Is there a process to follow-up with patients who are overdue for ACHD care?	Yes	No Unsure
Outreach Sites and Private Practice		
42. Does your ACHD program have outreach sites (i.e., clinics that are at places outside of	Yes	No Unsure

the main ACHD campus)?		
43. (If yes): do patients who receive care at outreach sites receive the same transition activities and support as those from your program?	Yes Unsure	No If no, please explain
44. Do any of your pediatric cardiology patients come from outreach sites?	Yes	No Unsure
45. (If yes): did patients from outreach sites appear to receive the same amount of transition activities and supports as those from the pediatric cardiology program?	Yes Unsure	No If no, please explain
46. If applicable: did pediatric cardiology patients from private practice appear to receive the same amount of transition activities and supports as those from other health care systems?	Yes Unsure	No If no, please explain_____
Miscellaneous		
47. What are the top three main barriers experienced by your team and youth when youth transfer from any pediatric cardiology program to your ACHD program?	1. _____ 2. _____ 3. _____	
48. Please include any additional information here regarding your programs transitional care that you feel may be pertinent to this study.		
49. What is your role in the ACHD program?	Free text: _____	

50. Would you mind if we contact you for further information?	Yes. (Please can you provide your contact details including name and email address)	Prefer not to
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Supplement 2

Survey Question Changes Based on the Original

Final	Original	Comments
Institution and patient population		
51. Name of hospital.	Name of hospital	
52. Name of adult congenital heart disease (ACHD) program.	Name of the GUCH programme	Revised to fit the US context
53. Director of the ACHD program.	Head of the department	Revised to fit the US context
54. By your best recollection what year was your ACHD program established?	Year in which the GUCH programme started	Revised to fit the US context
55. Is your ACHD program accredited?		New question
56. (If yes to above) Is your program accredited by the Adult Congenital Heart Association?		New question
57. From where are pediatric cardiology patients transferred to your program? (select multiple)		New question
58. <i>Based on the program from where the majority of your patients with CHD are transferred: is your ACHD program co-located in the same health care system with a pediatric cardiology program?</i>		New question
59. What is the distance between your ACHD and the pediatric cardiology program (from where the majority of your patients with CHD are transferred)? Range provided.		New question
60. What is the approximate size of the metro area where your ACHD program is		New question

located? A population of: (range provided).		
61. What proportion of your population has public health insurance (such as Medicaid, Medicare, or State sponsored plans)? (Best estimate. Skip to the next question if unsure).		New question
62. What proportion of your families are English speaking? (Best estimate. Skip to the next question if unsure).		New question
Transition facility and staff		
<p>Definition: Formalized congenital heart disease transition program: “Improving patient knowledge, self-management, and self-efficacy skills to the level they are capable to eventually integrate smoothly into adult-oriented health care.”</p> <p>John, A. S., Jackson, J. L., Moons, P., Uzark, K., Mackie, A. S., Timmins, S., ... & Gurvitz, M. (2022). Advances in managing transition to adulthood for adolescents with congenital heart disease: a practical approach to transition program design: a scientific statement from the American Heart Association. <i>Journal of the American Heart Association</i>, 11(7), e025278</p>	<p>Formalized Transition programme: “Offering education to support the medical, psychosocial, and educational/ vocational needs of adolescents as they move from the child-focused to the adult-focused healthcare system.”</p> <p>Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions: a position paper of the Society for Adolescent Medicine. <i>Journal of Adolescent Health</i>, 14(7), 570-576.</p>	Updated
63. Do you have a formalized transition program for patients with CHD according to the definition above?	Do you have a formalized transition programme for youth with CHD in your institution according to the definition above?	Revised to fit the US context
64. Does your ACHD program have a written protocol to guide transition activities?	Do you have a written transition plan/protocol that you offer to young patients in the transition programme?	Revised to fit the US context
65. What roles are represented in delivering core transition services as part of your formalized program.	Professional background of your dedicated transition specialists at your centre	Revised to fit the US context
Clinical preparation activities		

<p>66. What kinds of transition activities does your ACHD program offer? (Multiple responses possible).</p>	<p>What kind of transition intervention do you offer? Group sessions One-to-one counselling other</p>	<p>Added: Online transition preparatory module, handout with links and resources, referral to an outside transition focused clinic, one time transition counseling partnered with same day clinic visits, serial transition counseling partnered with same day clinic visits , one-to-one counseling not partnered with same day clinic visits (happen on separate days)</p>
<p>67. What transition model does your ACHD program use?</p>		<p>New question</p>
<p>68. Which of the following transition tools does your ACHD program use?</p>		<p>New question</p>
<p>69. How many transition encounters does a patient receive at your ACHD program (if applicable)?</p>	<p>Average time spent with the patient for the transition consultation.</p>	<p>Revised to fit the US context</p>
<p>70. Does your transition program have formal metrics measuring success of your transition program?</p>		<p>New question</p>
<p>71. Is there a different process to support transition of patients with developmental delay at your ACHD program?</p>		<p>New question</p>
<p>72. Is there an electronic medical record transition workflow to document and track/monitor transition activities?</p>		<p>New question</p>
<p>73. Do patients at your ACHD program have access to their pertinent medical records via a patient portal or other means?</p>	<p>Does the youth receive a detailed medical record before leaving paediatric care?</p>	<p>Revised to fit the US context</p>

<p>74. How much transition preparation do patients appear to have received prior to transfer to your ACHD program (from where the majority of your patients with CHD are transferred)?</p>		<p>New question</p>
<p>75. Do you have multidisciplinary transition meetings to discuss high risk youth transferring from pediatric cardiology to your ACHD program?</p>		<p>New question</p>
<p>Transfer activities</p>		
<p>Transfer Definition: Transfer of care is "the actual point in time when a patient's care moves from a pediatric to an adult health care professional or team." John, A. S., Jackson, J. L., Moons, P., Uzark, K., Mackie, A. S., Timmins, S., ... & Gurvitz, M. (2022). Advances in managing transition to adulthood for adolescents with congenital heart disease: a practical approach to transition program design: a scientific statement from the American Heart Association. <i>Journal of the American Heart Association</i>, 11(7), e025278.</p>	<p>Structured CHD Transfer: A structured transfer is defined as "an event on which adolescents and their parents move their care from the paediatric to the GUCH programme." Meadows, A. K., Bosco, V., Tong, E., Fernandes, S., & Saidi, A. (2009). Transition and transfer from pediatric to adult care of young adults with complex congenital heart disease. <i>Current cardiology reports</i>, 11(4), 291-297.</p>	<p>Updated</p>
<p>76. Do you have a transfer process from pediatric cardiology to ACHD at your institution according to the definition above (from where the majority of your patients with CHD are transferred)?</p>	<p>Do you have a systematic transfer from paediatric cardiology to GUCH at your institution according to the definition above?</p>	<p>Revised to fit the US context</p>
<p>77. Is there a structured age at which pediatric patients are handed off to your team (from where the majority of your patients with CHD are transferred)?</p>	<p>At what age are patients transferred to your GUCH program</p>	<p>Changed response from flexible ranging from ____ to ____y to flexible age based on development.</p>
<p>78. Please estimate the number of patients that transferred from pediatric cardiology to</p>	<p>Number of patients that did their transfer from paediatric cardiology to your GUCH clinic in 2016</p>	<p>Revised to fit the US context</p>

your ACHD program in 2022. (If unknown leave blank).		
79. Is there an option for the patient to visit the ACHD clinic prior to transfer from pediatric cardiology clinic?		New question
80. Is there an option for the patient to meet with an ACHD team member at the last pediatric cardiology appointment?	Do you offer joint or overlapping appointments,, or visits to the adults's services with someone from paediatric cardiology services?	Revised to fit the US context
81. Does the pediatric cardiology team transfer all CHD patients who are aging into adult care to your institution or only select patients? (e.g., only complex defects)	Do the paediatricians transfer all GUCH patients to your institution or only select patients (eg. Only complex defects)?	Revised to fit the US context
82. Is a transfer/referral order placed by the pediatric cardiology program to your ACHD program?		New question
83. Is an ACHD provider identified during the transfer process by the pediatric team?		New question
84. Is a formal transfer summary created during the transition process by the pediatric cardiology team?	Do you receive a medical record from the paediatrician?	Revised to fit the US context
85. Does your ACHD program offer outreach by a scheduling specialist to help patients make their first appointment? (e.g., 2 phone calls and a letter by a support staff member?)		New question
86. Do you have a process to follow-up with patients who did not successfully transfer from pediatric		New question

cardiology to your ACHD program?		
Integration Activities		
<p>Definition: Integration is the process of establishing care in an adult model of care that can fully meet a patient's complex needs.</p> <p>Rosen, D. S., Blum, R. W., Britto, M., Sawyer, S. M., & Siegel, D. M. (2003). Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. <i>Journal of Adolescent Health, 33</i>(4), 309-311.</p>		New question
87. Is a welcome letter sent to the patient/family from your ACHD program?		New question
88. Does your ACHD program track 'no show' patients to call them and reschedule the appointment?		New question
89. Are patients sent text messaging appointment reminders?		New question
90. Does your ACHD program measure how many patients keep their SECOND follow up in the ACHD clinic?		New question
91. Is there a process to follow-up with patients who are overdue for ACHD care?		New question
Outreach Sites and Private Practice		
92. Does your ACHD program have outreach sites (i.e., clinics that are at places outside of the main ACHD campus)?		New question
93. (If yes): do patients who receive care at outreach sites receive the same transition activities and support as those from your program?		New question

94. Do any of your pediatric cardiology patients come from outreach sites?		New question
95. (If yes): did patients from outreach sites appear to receive the same amount of transition activities and supports as those from the pediatric cardiology program?		New question
96. If applicable: did pediatric cardiology patients from private practice appear to receive the same amount of transition activities and supports as those from other health care systems?		New question
Miscellaneous		
97. What are the top three main barriers experienced by your team and youth when youth transfer from any pediatric cardiology program to your ACHD program?	4. _____ 5. _____ 6. _____	New question
98. Please include any additional information here regarding your programs transitional care that you feel may be pertinent to this study	If you would like to share any additional information with us, please let us know!	
Miscellaneous		
99. What is your role in the ACHD program?	Name and email of the respondent	Revised to fit the US context
100. Would you mind if we contact you for further information?		New question

CHAPTER V

Discussion, Summary, & Implications

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Discussion

Given advances in medical and surgical care, congenital heart disease (CHD) is considered a life-span disease requiring ongoing specialized cardiac care (Mandalenakis et al., 2020). Patients with CHD are in a vulnerable position during the transition years, placing them at risk of experiencing gaps in care which may lead to negative health outcomes (Yeung et al., 2008). Transition programs offer structured support to patients with the aim of improving CHD knowledge, independence in care, and providing an uninterrupted transfer process and integration into accredited adult congenital heart disease (ACHD) programs. (A.S. John et al., 2022; Moons, Bratt, et al., 2021). The main barriers to successful transition program implementation are time and resources to complete transition activities and there is no best model for transition programs. The percentage of patients that successfully transfer from pediatric cardiology to ACHD programs in the US is low, despite transition program interventions (S. S. Gaydos et al., 2020; Vaikunth et al., 2018). Patients in the US are also more likely to experience gaps in care during the transition years (Moons, Skogby, et al., 2021) compared with Canada and Europe. We determined that studies are needed to 1) explore low resource interventions to facilitate transition, 2) identify factors that improve effective transfer, and 3) evaluate transition practices in the US. To address these gaps, we sought to 1) to test a low resource transition activity for pediatric patients with congenital heart disease in the ambulatory care setting, 2) to quantify differences in time to transfer to ACHD centers between patients with moderate and great complexity CHD who received structured transfer support versus those who did not, and 3) characterize ACHD transition practices across the US. Hence, this discussion presents a summary of the findings, along with an integration with previous research, centered on the three transition components: 1) preparation, 2) transfer, and 3) integration. Following this, in the section on summary and implications, we summarize the program of research, describe theoretical, methodological and clinical implications, and suggest directions for the research in the above three transition components.

Preparation

As we previously mentioned, formal transition programs aim at preparing pediatric cardiology patients for successful lifelong management of their chronic disease by fostering knowledge of their CHD and teaching self-management and self-advocacy skills within a structured program (A. S. John et al., 2022; Mackie et al., 2019; Moons, Bratt, et al., 2021; White et al., 2020; White et al., 2018). In Chapter I, we highlighted that 42% of surveyed ACHD European programs (Thomet et al., 2021) and 71% of surveyed pediatric cardiology programs in North America (Basile et al., 2023) reported the presence of formal transition programs and that the presence of formal transition programs in ACHD programs in the US is unknown. In Chapter IV, we addressed this gap and learned that 68% of surveyed ACHD programs reported the presence of a formal transition program.

In Chapter I, we explored a variety of transition models used by transition programs. The most commonly reported models were nurse-led (Goossens, Fieuws, et al., 2015; Ladouceur et al., 2017; Mackie et al., 2014; Mackie et al., 2022; Mackie et al., 2018; Ricci et al., 2023), and the most complete model was a comprehensive transition model which was staffed by a trained transition coordinator (E. L. Bratt et al., 2023). What we found was that there was little consistency in transition program composition as well as outcome measures of program success, and no comparison studies, making it hard to decipher which program models are best. In Chapter II, we tested another potential transition model: a medical assistant (MA)-facilitated transition activity. What we found was that this activity led to increased documentation of transition discussions in the pediatric cardiology clinic. This activity was also rated as acceptable by staff. Findings from this study were encouraging as no additional staff were needed to conduct this activity. In Chapter IV, we gained information about transition models used by surveyed ACHD programs in the US. What we learned was that physicians were the most commonly reported staff members conducting core transition activities and a pediatric

cardiologist-led clinic-based model was one of the most commonly reported models. This may be due to limited resources allocated toward transition activities, which if true, could increase physician workload burden. Few programs surveyed reported having staff to provide specialized mental health support.

In Chapter I, we explored transition practices offered within transition programs. What we learned was that the most frequently reported education topics offered by transition programs were related to ‘the heart defect’ (E. L. Bratt et al., 2023; S. S. Gaydos et al., 2020; Goossens, Fieuws, et al., 2015; Ladouceur et al., 2017; Mackie et al., 2014; Mackie et al., 2022; Mackie et al., 2018; Ricci et al., 2023) and ‘current treatment and medications’ (E. L. Bratt et al., 2023; S. S. Gaydos et al., 2020; Goossens, Fieuws, et al., 2015; Ladouceur et al., 2017; Mackie et al., 2014; Mackie et al., 2022; Mackie et al., 2018; Ricci et al., 2023). Interestingly, in Chapter II, we learned that ‘the name of your heart condition and any surgeries’ (38%) and ‘the names of your medications and what they are used for’ (35%) were also the top two requested and discussed topics in the MA-facilitated activity. We did not explore education topics addressed by ACHD programs in Chapter IV, as the addition of a list of education topics to the survey of transition practices at ACHD programs may have been burdensome.

In Chapter I, we learned that measures of readiness for transition (E.-L. Bratt et al., 2023; S. S. Gaydos et al., 2020; Mackie et al., 2014; Mackie et al., 2022; Mackie et al., 2018) and measures of cardiac knowledge (Goossens, Fieuws, et al., 2015; Ladouceur et al., 2017; Mackie et al., 2014; Mackie et al., 2022; Mackie et al., 2018; Ricci et al., 2023) were the most frequently used measures within transition programs. In Chapter IV, we learned that this was true for surveyed ACHD programs in the US as well.

In summary, we addressed a gap in the research by now having a better understanding of the presence of formal transition programs in ACHD programs in the US. We also learned that a low resource MA-facilitated activity may be a suitable transition program activity in the pediatric

cardiology clinic setting, but more studies are needed to examine this model's long-term outcome on patient readiness for transfer as well as successful transfer to ACHD. ACHD programs appear to need more support staff to deliver key transition interventions, such as specialized mental health support. Compared with other transition programs, patients in our MA-facilitated study reported requesting similar education topics and ACHD programs reported utilizing similar transition measures offered by other programs.

Transfer

In Chapter I, we learned that international transition recommendations support a structured transfer process (Moons, Bratt, et al., 2021). Structured transfer processes are commonplace in Europe (88.5%) but current transfer practices in the US were unknown (Thomet et al., 2021). We addressed this gap in Chapter IV, by examining the presence and the components of structured transfer processes at surveyed ACHD programs in the US. What we learned from our findings was that 70% of the surveyed ACHD programs reported the presence of structured transfer processes. We also have a benchmark on what these transfer practices are comprised of, such as transfer age, placement of a referral order, options to meet an ACHD team member prior to transferring, and others.

In Chapter I, we examined transfer occurrence from pediatric cardiology to ACHD programs and we learned that in the US, between 11-39% of CHD patients successfully transfer (Bohun et al., 2016; S. S. Gaydos et al., 2020; Gerardin et al., 2019; Goossens, Fernandes, et al., 2015; Harbison et al., 2016; Kollengode et al., 2018; Norris et al., 2013; Vaikunth et al., 2018). In Chapter III, almost half of patients with moderate or great complexity CHD successfully transferred to an ACHD program in our study, and those with a referral order had more successful transfers. We also learned that placement of the referral order led to sooner time to transfer. However, in Chapter IV, we learned from survey respondents that under half of

pediatric cardiology programs place a referral at time of transfer. Thus, referral order placement may be one way to improve the current mediocre transfer rates in the U.S.

In Chapter I, we learned that retention in pediatric cardiology during the transition years in the US ranges between 21% to 69% (Bohun et al., 2016; Gerardin et al., 2019; Goossens, Fernandes, et al., 2015; Harbison et al., 2016; Kollengode et al., 2018; Norris et al., 2013). In Chapter III, we found that retention in pediatric cardiology care in our study was 31%. We did not examine reasons for retention in pediatric cardiac in Chapter II, however. Survey results from Chapter IV confirmed that not all patients in the US are transferred from pediatric cardiology to ACHD programs. The reasons given in free text responses indicated that some pediatric cardiologists wait until patients' complete college, wait until patients are too old to be in pediatric cardiology, go by patient request to remain in pediatric cardiology, or they hold onto patients until an event, such as pregnancy.

In Chapter I, we learned that International guidelines recommend transfer processes for patients with developmental delay, but it is not clear what type of supports are in place for facilitating transfer for patients with developmental delay, such as processes establishing medical power of attorney for those with severe developmental delay, or a shared decision-making pathway for those with less severe developmental delay (A.S. John et al., 2022). In Chapter IV, we learned that only 22% of the ACHD programs surveyed had processes in place to support patients with developmental delay.

In summary, we addressed a gap in the research and now have an understanding of the presence of structured transfer processes from the perception of surveyed ACHD programs in the US. Placement of a referral order is a necessary component of a structured transfer process. More studies are needed to gain a better understanding of retention in pediatric programs from the perspective of pediatric cardiology programs. Lastly, more studies are

needed to examine processes that provide structured support for those with developmental delay to help them and their families navigate the transfer process.

Integration

As mentioned in Chapter I, studies are needed to increase our understanding of integration practices at ACHD programs. We addressed this gap in Chapter IV, and we now have an understanding of current integration practices offered at the ACHD programs surveyed.

In Chapter I, we mentioned that international recommendations suggest finding methods to address gaps in CHD care (A.S. John et al., 2022), and that gaps in care in the US are reported to be around 34% (Moons, Skogby, et al., 2021). In Chapter III, around 17% of patients experienced a gap in care in our study, and significantly more patients experienced a gap in care with no referral order than those with a referral order. In Chapter IV, just over 30% of programs reported having formal metrics in place to measure successful transfer to ACHD, however, almost 90% of programs reported having a process to track and reschedule patients who did not arrive at their scheduled appointment with ACHD. Just over half of programs reported having a follow-up process in place for patients who are overdue for ACHD care.

In summary, this is the first program or research to explore integration practices into ACHD programs in the US, and we now have a limited benchmark of what these practices entail. Gaps in care in our study (Chapter III) were lower than were previously reported in the US, and lowest in patients with a referral order in place, supporting the recommendation that referral order placement should be a component of a structured transfer process. It was encouraging to see that many surveyed ACHD programs had processes in place to support ongoing cardiac care.

Summary and Implications

In summary, transition programs are necessary for helping patients with CHD navigate the transition years. Transition contains three components: preparation, transfer and integration.

The main barriers to successful transition program implementation are time and resources to complete transition activities and there is currently no best model for transition programs. In the US, patients with CHD have lower transfer occurrence and they experience more gaps in care compared with patients in Europe and Canada. The collective body of work set forth in this program of research explored methods within each transition component to overcome some of the barriers and address some of the gaps in research. First, we addressed some of the barriers by examining an alternative low resource transition model: a MA-facilitated CHD transition activity. We learned that a MA-facilitated transition activity may aid in patient preparation, and it appears to be a suitable model for the pediatric cardiology clinic setting. Second, we also learned that a second low resource intensive practice: placement of a referral order leads to improved transfer outcomes to ACHD programs, and it should be a necessary component of a structured transfer process. These findings are important as we mentioned that patients with CHD in the US experience lower percentage of transfer to ACHD programs and experience higher rates of gaps in care during the transition years compared with Canada or Europe.

We addressed a gap in the research by exploring the presence of formal transition programs and practices at surveyed ACHD programs in the US. What we learned was that over two-thirds of respondents reported the presence of formal transition programs. We also addressed a gap in the research by exploring the presence of structured transfer processes for CHD patients in the US from the perspectives of these surveyed programs. Over two-thirds of respondents reported using structured transfer processes. Our survey was also the first to explore integration practices into ACHD programs in the US and internationally. We now have a benchmark of these transition practices across all three transition components in the US which helps us generate amenable targets for intervention to optimize transition practices, such as a need for additional support staff within these programs and processes to support patients with developmental delay.

Implications

Theoretical Implications

A national initiative on health care transition, the Six Core Elements of health care transition™, supplies us with the basic components of a structured transition process. Within this program of research we customized the Six Core Elements™ approach to the CHD transition subspecialty with the following goals in mind: 1) improve the ability of youth and young adults with CHD to manage their own health care and effectively use health services, and 2) ensure an organized process in pediatric and adult health care practices to facilitate transition preparation, transfer of care, and integration into ACHD programs. We addressed these goals by 1) increasing documented transition discussions that were geared towards patients understanding the heart defect, managing their own CHD care and effectively using CHD and other health services and 2) necessitating referral order placement as a component of a structured transfer process, and 3) supplying a benchmark of transition preparation, transfer and integration practices in the US, and in doing so, highlighting a need to augment support staff, such as psychologists and psychiatrists. With these findings we have a better understanding of what practices are needed to support a structured transition process, such as the need for additional support staff.

Within this program of research, we also explored all of the Six Core Elements™ transition components (preparation, transfer and integration). Within the preparation component we tested a low resource transition activity that is suitable for use in the CHD clinic setting. We also supplied data of current transition preparation practices in the US from the perspective of ACHD programs. Within the transfer component we added the importance of a referral order as an aspect of a structured transfer process. We also provided data on the presence of structured transfer practices from the perspective of ACHD programs. In the integration component we provided data on ACHD program integration practices. This was a suitable framework to explore CHD transition within the health care system. Once available, the updated health care transition

theoretical model, which was originally developed by Betz and colleagues, will be a good fit for future research as it adds patient and family perspectives as well as those related to the patient and family's environment (Betz et al., 2014).

Methodological Implications

Our body of research was mostly exploratory in nature. We did, however, test a low resource intervention in a real-world setting. We used a well validated questionnaire to assess staff acceptability of the MA-facilitated transition activity: the revised Treatment Acceptability and Preference Questionnaire (Sidani, Miranda, et al., 2009). This questionnaire was designed to test divergent views of the acceptability of treatments, such as divergent views between patients and the healthcare team. In our study, however, we only tested a single view. We applied time to event analyses to time to transfer to ACHD programs to see not only if patients transferred to ACHD programs but when. Lastly, we used a previously applied well-developed survey to benchmark US practices to European practices. The survey can be used again in the future.

Clinical Implications

By conducting the proposed research, there are several important implications for practice. First, we have a better understanding of the presence of formal transition programs and practices in ACHD programs in the US. By having a better understanding of CHD transition practices in the US, we can generate amenable targets for intervention to optimize transition practices. We determined, however, that more support staff are needed within ACHD programs to fully support transition practices, such as specialized mental health support. Second, by testing a MA facilitated transition intervention, we made clinical contributions by demonstrating increased documented transition discussions in the pediatric cardiology clinic without the use of additional resources such as staff, and clinic space. We also learned what CHD transition education topics are most commonly requested and discussed in the pediatric cardiology clinic and that the activity is rated as acceptable by staff. Third, we also have a better understanding

of structured transfer practices to ACHD programs in the US and we identified that there is a need to establish processes to support patients with developmental delay during the transfer process. Fourth, by examining differences in time to transfer to ACHD centers between patients with moderate and great complexity CHD who received a referral order versus those who did not, we have a better understanding of another low-resource practice that may improve successful transfer outcomes. As mentioned previously, placement of a referral order is not a resource-intensive process, and no additional staff are required, and it should be a component of a structured transfer process. Lastly, we now have a better understanding of integration practices into ACHD programs in the US. Attention to integration practices may enhance continuity in care and decrease the risk of gaps in care during the transition years.

Strengths

This program of research has a number of strengths. First, as described above we selected a robust measure to assess staff acceptability of the MA-facilitated intervention. We also modified an existing survey to learn more about transition practices in the US. Secondly, we used robust statistical approaches, such as generating time-to-transfer curves using Kaplan-Meier graphs and the log-rank Mantel-cox test and cox proportional hazard regression modeling to analyze time to transfer. Thirdly, we presented the data in a manner that could be easily translated into clinical practice, such as by showing that low resource interventions may yield positive transition outcomes and providing a benchmark of current transition practices in the US. Finally, our research team collaborated with national (PW and KU) and international (CT and PM) ACHD transition experts.

Limitations

The limitations of this program of research should be noted. First, all analyses were performed on cross-sectional data, thus we were not able to draw any conclusions on any long-term outcomes. Second, except for the survey study of transition practices in the US, our data were

collected from a single tertiary care center. Hence, our findings are limited by the perspectives and practices of this center. Thirdly, apart from the MA-facilitated transition intervention, our studies were limited by a small sample size, and across all studies we lacked patient and family perspectives. Fourthly, apart from the study examining referral order placement on time to transfer, our studies may be limited by response bias. Participants in the MA-facilitated study may have placed more effort in increasing transition discussions knowing that they were taking part in the study, and surveyed ACHD centers may have been more inclined to complete the survey if they had formalized transition programs. Hence, these results should be interpreted with caution. Finally, our program of research could have benefited from evaluating developmental delay as a covariate in the cox proportional hazard regression modeling in analyzing time to transfer, as well as perceived percentages of successful transfer to ACHD in our transition activities in the US. These may have yielded interesting results.

Future Research

Despite the significant and meaningful contributions made by this program of research, there is still a critical need to further CHD transition research within each transition component: preparation, transfer and integration. Within this program of research, there is a need to examine additional aspects of patient preparation. We need to gain a better understanding of transition practices at pediatric cardiology clinics across all settings (university clinics, private practice and satellite sites) and design interventions to maximize patient preparation for transfer to ACHD programs. There appears to be a lack of support staff to support transition practices at ACHD programs. This is an area requiring further research. Additionally, there is a need to examine long term outcomes of the MA-facilitated transition activity, such as its impact on patient readiness and successful transfer. Patient and family perspectives were excluded in this study and more research is needed to explore these. If additional studies support this low resource transition activity, implementation science methodology could facilitate the uptake of

this activity into routine pediatric cardiology clinic practice. Lastly, the MA facilitated transition activity may also be suited for the ACHD setting. More research is needed to explore this possibility.

Within this program of research, there is a need to examine added aspects of patient transfer to ACHD programs. We need to gain a better understanding of transfer practices at pediatric cardiology clinics across all settings (university clinics, private practice and satellite sites) when transferring a patient to ACHD programs and design interventions to maximize successful transfer to ACHD programs. More studies are needed to gain a better understanding of retention in pediatric cardiology in the US programs from the perspective of pediatric cardiologists and patients and more studies are needed to examine processes that provide structured support for those with developmental delay to help them and their families navigate the transfer process. We need to examine the impact of referral order placement within other pediatric cardiology clinic settings to see if our findings translate to other settings, such as transfer occurrence and time to transfer to ACHD programs. Additionally, we need more studies examining other components of the structured transfer process so that we can have a better understanding of their impact on transfer outcomes. Lastly, within this program of research, there is a need to examine all aspects of patient integration into ACHD programs, such as their impact on promoting continuity in care, so that interventions can be designed to maximize this process and potentially decrease gaps in care during the transition years.

Conclusions

In conclusion, the body of work presented here demonstrates advances in CHD transition research along with important theoretical, methodological, and clinical implications. There is a need for further research, however, to continue expanding our understanding of transition programs design, and effectiveness in aiding patient preparation, transfer and integration into ACHD care.

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