

Original Article

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Transition of adolescents with congenital heart disease from pediatric to adult congenital cardiac care: lessons from a retrospective cohort study

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Abstract

Background: The transfer from pediatric to adult care is a key milestone for adolescents living with chronic health conditions. Over the past few decades, pediatric cardiac care has witnessed outstanding advancements leading to a dramatic increase in the number of children with congenital heart disease (CHD) surviving into adulthood. Successful transfer from pediatric to adult congenital cardiac care is critical because many adults with CHD require regular long-term cardiac care for optimal health outcomes.

Objectives: This study aims to (1) determine the rate of successful transfer of adolescents with CHD from pediatric to adult congenital cardiac care at the McMaster University Medical Centre (MUMC), a tertiary care level centre, and (2) to explore available patient- and context-related factors associated with unsuccessful transfer. MUMC includes both the McMaster Children's Hospital, which offers

Pediatric Cardiology services, and Adult Outpatient Services, which offers the Adult Congenital Cardiac Clinic (ACCC).

Methods: This is a retrospective cohort study in which all patients eligible for transfer from pediatric to adult congenital cardiac care from January 2006 to December 2012 were identified from the McMaster Children's Hospital database. Successful transfer was defined as attendance at the ACCC within 2 years of discharge from Pediatric Cardiology. Patient and context-related variables include gender, severity of the CHD diagnosis, years since pediatric follow-up, and distance from the patient's home to MUMC. The relationship between patient- and context-related variables available at baseline and unsuccessful transfer was assessed by univariate analysis.

Results: A total of 279 patients were identified, of which, 269 patients (96.4%) were successfully transferred to adult congenital cardiac care. Out of the 10 patients (3.6%) who were lost to follow-up, 8 had mild, 1 had moderate, and 1 had severe CHD. Based on the point estimates expressed as odds ratio (OR), factors that are potentially associated with a higher risk for loss to follow-up were: male gender (OR 1.8, 95% CI 0.5–7.3) and travel distance greater than 200 km to MUMC (OR 7.7, 95% CI 0.7–81.5), while moderate and severe CHD could potentially be a protective factor against loss to follow up when compared to mild CHD (OR 0.2, 95% CI 0–1.1).

Discussion: The medical and administrative practices that may be contributing to the high transfer rate of 96.4% include early and developmentally appropriate discussions, engaging patients and their families in cardiac care, proximity of the pediatric and adult congenital cardiac clinics, and an information pamphlet regarding the transition process, amongst others. Learning from our retrospective study we now work with the patients identified as potential high risk for loss to follow-up to understand and eliminate barriers and to implement sustainable methods that will ensure a successful transition to adult health care for all patients with CHD.

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Keywords: adolescents; adults; congenital heart disease; retrospective cohort study; transfer; transition.

Introduction

Significance of the continuity of cardiac care

The transition from adolescence to adulthood is challenging for young individuals with chronic health conditions. These individuals become responsible for their health management while facing additional life challenges such as higher education, starting a career, and moving out of their parents' home [1]. A key element of this transition to adulthood is the transfer of individuals from pediatric services to adult health care settings. While the divide in the pediatric and adult health care system often limits the ability to track the outcomes after transfer, clinicians in pediatric care are encouraged to evaluate their success rates of transitioning young people. This study assesses the transfer of adolescents with congenital heart disease (CHD) from pediatric to adult congenital cardiac care at the McMaster University Medical Centre (MUMC), a tertiary care level centre in Hamilton, Ontario, Canada. MUMC includes both the McMaster Children's Hospital, which offers Pediatric Cardiology services, and Adult Outpatient Services, which offers the Adult Congenital Cardiac Clinic (ACCC).

CHD is considered the most common birth defect with an estimated incidence of 0.8% in neonates [2]. Recent advancements in pediatric cardiac care including diagnostic modalities, medical therapies, and surgical and catheter-based interventions have dramatically increased the number of children with CHD surviving into adulthood [3]. Currently, between 80% and 85% of children with CHD survive into adulthood with an estimated 100,000 Canadian and 1 million American adults living with CHD [4, 5]. After a catheter-based or surgical cardiac intervention, many CHD patients, particularly those with complex lesions, require life-long care. This highlights the importance for cardiac care to extend into adulthood [6]. According to the Canadian medical guidelines, more than 50% of adults living with CHD are recommended to regularly follow-up with an adult cardiologist specializing in CHD every 12–24 months [4, 7–10].

Studies have shown that less than 50% of children with CHD are successfully transferred to adult congenital cardiac care [11–13]. Reid et al. reported a 47% (95% CI: 42–52) transfer rate for patients aged 19–21 years with complex CHD between the Hospital for Sick Children and the Toronto Congenital Cardiac Centre for Adults in

Ontario, Canada [11]. According to Mackie et al., only 39% of patients between 18 and 22 years old were still being seen in outpatient cardiology in Quebec, Canada [12]. Failure to maintain continuous cardiac care into adulthood can delay recognition of evolving and new cardiac problems, thus increasing the risk of negative health complications and premature mortality [14–16]. Complications that adults with CHD may develop include arrhythmias leading to sudden cardiac death, progressive heart failure, [16, 17] and the risk of reoperation [18, 19]. For these reasons, the successful transfer of patients with CHD from pediatric to adult congenital cardiac care is of particular importance.

Transfer vs. transition of care

The terms 'transfer' and 'transition' of care are related but not synonymous. Transfer of care is an event that occurs at some point during pediatric care in which the patient is transferred to adult care [20]. In the pediatric cardiac care setting, it implies that the patient has been discharged from the pediatric cardiac care program with a referral to follow-up with the adult congenital cardiac care program.

On the other hand, transition of care is a continuous process that occurs over years, and can start even before reaching adolescence. It works at enabling the patient to take charge and responsibility of their life and health [21]. It aims at preparing the patient to be followed-up by the adult care program, and it often requires a collaboration between the patient, their family, and the pediatric and adult health care providers [22]. The American Academy of Pediatrics states that "the goal of transition in health care for young adults with special health care needs is to maximize life-long functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood" [23]. The importance of cardiac care transition was raised in the five task-force reports obtained from the Bethesda conference on the care of the adult with CHD [4, 7, 24–26].

Objectives

This study aims to (1) determine the rate of successful transfer of adolescents with CHD from pediatric to adult congenital cardiac care at a single tertiary care level centre – McMaster University Medical Centre located in Hamilton, Ontario, and (2) to evaluate available patient- and context-related factors associated with unsuccessful transfer.

Methods

Setting

The study evaluated our services at McMaster Children's Hospital, a tertiary care level pediatric academic hospital located in Hamilton, Ontario, Canada. It serves health-care to children and youth up to 18 years of age in a wide range of pediatric specialties, including pediatric cardiology. Our transition service is integrated in routine clinical practice, and delivered by the Pediatric Cardiologists from the Department of Pediatrics. A transition pamphlet is provided prior to the actual transfer process (Supplemental Figure 1). Recently, in collaboration with the CanChild Centre for Childhood Disability Research at McMaster University, we have implemented the MyTransition mobile phone application available on the Apple App Store and Google Play Store [27, 28]. The app contains the Transition-Q questionnaire which tracks the development of skillset required in health management [29]. The Pediatric and ACCC are located at the same site in Hamilton. This enables that all tests including ECG, holter, and exercise tests are done in the same place. If patients miss their appointment with the Pediatric or Adult service, they are contacted by the respective departments via telephone call. The ACCC has a dedicated nurse practitioner who contacts the patients. When patients miss their appointment, a mailing letter is sent and if we are unable to contact the patient via telephone more than twice, their GP is contacted.

Study design and data collection

This is a retrospective cohort study that included all patients who were eligible for transfer from pediatric to adult congenital cardiac care from January 2006 to December 2012, with ages ranging from 17 to 26 years, based on the Canadian Cardiovascular Society (CCS) consensus criteria [8–10]. No exclusion criteria were set in the study. The data were obtained from the McMaster Children's Hospital database.

Rate of successful transfer

The primary outcome in the study was the successful transfer of children with CHD from Pediatric Cardiology to the Adult Congenital Cardiac Clinic at MUMC. Successful transfer was defined as attendance (original or rescheduled appointment) at the ACCC within 2 years of discharge from Pediatric Cardiology. This definition fits the

time frame recommended by most pediatric cardiac clinics based on resources and demands placed on the clinics. However, adult congenital cardiac clinics try to provide appointments to patients within 1 year from their last appointment with the pediatric cardiac care program.

Predictors of unsuccessful transfer

Baseline data were obtained from patient charts to potentially identify predictors of unsuccessful transfer. Such data include (1) gender, (2) severity of CHD, and (3) distance from MUMC. The severity of the cardiac diagnoses was classified into mild, moderate or severe using the Adult Congenital Heart Disease Consensus Statement [30]. MUMC is located on the same site as the McMaster Children's Hospital, and includes the McMaster Children's Hospital, Women's Health Centre, and the Adult Outpatient Services, where the ACCC is located. The linear distance to MUMC, which contains both the pediatric and adult congenital cardiac clinics was calculated based on the postal code of the patient's residence. In addition, the patient population was stratified based on the time (in years) since their last pediatric follow up. This was to assess any difference in transfer rates over the study period of January 2006 – December 2012. For example, 2 years since pediatric follow up means 2 years prior to 2012. Additional data reviewed in the study include attendance at the pediatric cardiology clinic appointments as well as documentation of the recommended follow-up with adult congenital cardiac care. Any missing referrals to ACCC were reviewed and included in the study as well.

Ethical considerations

Ethical board approval was obtained from the Hamilton Integrated Research Ethics Board (HiREB) before conducting the study. To secure patient confidentiality, no personal information from any participant was utilized or shared in the process of conducting the study. Each participant was assigned a random number when collecting and analyzing the data, without referring to any personal information such as name or chart number.

Data analysis

Descriptive statistical analysis was utilized for variables available at study entry (i.e. baseline). The relationship between factors available at baseline and our outcome of interest, i.e. successful versus unsuccessful transfer was assessed by univariate analyses, and expressed as an odds ratio with 95% confidence interval.

Results

A total of 279 patients were identified and included in the study based on the inclusion criteria. Of these patients, 157 (56%) were male and 122 (44%) were female (Table 1). The years since pediatric follow up ranging from 0 to 8 years is shown in Table 1. A total of 269 (96.4%) patients were successfully transferred from Pediatric Cardiology to the ACCC at MUMC and 10 patients (3.6%) were lost to follow-up between January 2006 and December 2012.

We evaluated the demographics of our population according to patient- and context-related factors (Table 1). Approximately half of the reviewed patients (49.1%) had mild CHD, with the remaining patients having either moderate (37.3%) or severe (13.6%) CHD. Of the 10 patients who were lost to follow-up, 8 had mild, 1 moderate, and 1 had

severe CHD. Most participants (56.6%) were living within 50 kilometers (km) from McMaster Children's Hospital, 27% of patients were living >50 km and 2% of patients were living >200 km.

Out of the 10 patients who were lost to follow-up with the ACCC, 1 patient did not attend their last pediatric cardiology follow-up, 1 patient did not have a documented recommendation to follow-up with the ACCC and 2 patients were missing referrals to the ACCC (data not shown). Table 2 contains additional detailed information regarding the 10 patients who were lost to follow-up with the ACCC including their cardiac diagnoses, associated comorbidities, past surgical or catheter-based interventions, and any medications the patients were prescribed, divided into cardiac and non-cardiac medications.

Factors that are potentially influencing the risk of unsuccessful transfer are presented in Table 3. Due to the low number of patients who were lost to follow-up ($n = 10$) statistically significant associations could not be established as expressed in the wide 95% confidence intervals. However, the point estimates did demonstrate an increased risk for loss to follow-up for male patients (OR 1.8, 95% CI 0.5–7.3) and those travelling greater than 200 km to the hospital (OR 7.7, 95% CI 0.7–81.5). Next, moderate and severe CHD could potentially be a protective factor against loss to follow up when compared to mild CHD (OR 0.2, 95% CI 0–1.1). Also, patients seen in earlier years (>3 years prior to the study period) were potentially at a higher risk for loss to follow-up when compared to those seen in recent years prior to the study (OR 1.4, CI 0.4–5.2).

Table 1: Participants' demographic characteristics.

	All participants (n = 279)	
	Successful transfer (n = 269)	Unsuccessful transfer (n = 10)
Age (years)		
17–22, n (%)	180 (67)	8 (80)
>22, n (%)	65 (24)	2 (20)
Not available on chart, n (%)	24 (9)	0 (0)
Gender		
Females, n (%)	119 (44)	3 (30)
Males, n (%)	150 (56)	7 (70)
Severity based on ACHD rating		
Mild, n (%)	129 (48)	8 (80)
Moderate, n (%)	103 (38)	1 (10)
Severe, n (%)	37 (14)	1 (10)
Distance from patient's home to MUMC ^a		
<50 km, n (%)	153 (57)	5 (50)
50–200 km, n (%)	75 (28)	1 (10)
>200 km, n (%)	4 (1)	1 (10)
Not available in chart, n (%)	37 (14)	3 (30)
Years since pediatric follow-up		
0, n (%)	9 (3)	0 (0)
1, n (%)	34 (13)	0 (0)
2, n (%)	38 (14)	2 (20)
3, n (%)	44 (16)	4 (40)
4, n (%)	25 (9)	0 (0)
5, n (%)	30 (11)	2 (20)
6, n (%)	32 (12)	1 (10)
7, n (%)	32 (12)	1 (10)
8, n (%)	1 (0)	0 (0)
Not available on chart, n (%)	24 (9)	0 (0)

^aMUMC – McMaster University Medical Centre.

Discussion

McMaster Children's Hospital & the rate of successful cardiac transfer

The Pediatric Cardiology program at McMaster Children's Hospital recognizes the importance of successful transfer from pediatric to adult congenital cardiac care. Although the hospital does not have a formal transition program, we are excited to demonstrate in the cardiac clinic with an integrated approach to transition a high rate of successful transfer, 96.4%, exceeding many other figures reported in the literature. For instance, Reid et al. reported that 47% of adolescents with CHD underwent successful transfer of cardiac care in Toronto, Canada [11]. Their definition of successful transfer was attendance to at least 1 cardiac appointment of any type (e.g. clinic, echocardiogram, cardiac catheterization, or surgical), without specifying a timeframe, while in the current study, successful

Table 2: Demographics and relevant medical histories of patients lost to follow-up.

Case No. ^a	Age	Gender	Cardiac diagnosis	Co-morbidities	ACHD class	Surgery/intervention	Medication	Last visit
1	19	Male	1. Bicuspid aortic valve (mild AR ^b , mild AS ^c) 2. Coarctation of aorta 3. Hypertension	None	Moderate	1998 – balloon dilatation and stent placement 2005 – diagnostic angiogram	Bisoprolol 5 mg once daily	August 2010
2	20	Male	1. Corrected TGA ^d with supero-inferiorly related ventricles 2. VSD ^e 3. Right-sided AV ^f valve regurgitation 4. Second degree AV block	None	Severe	1992 – VSD closure 1994 – pacemaker insertion	None	None
3	20	Female	1. PDA ^g (very small left-to-right shunt)	Developmental delay	Mild	2010 – PDA repair	Non-cardiac	June 2012
4	19	Male	1. Perimembranous VSD (no leak) 2. Resection of RV ^h muscular bundles	Prematurity, ADHD, cleft palate, hypospadias, velopharyngeal repair	Mild	VSD repair	None	September 2010
5	22	Male	1. Small perimembranous VSD 2. Small-to-moderate ASD ⁱ 3. Premature ventricular contractions	None	Mild	None	None	May 2009
6	23	Female	1. Bicuspid aortic valve (no AR or AS) 2. Subaortic ridge (pg: 49 mmHg) 3. Mild LV ^k outflow tract gradient	Chromosomal disorder	Mild	None	None	January 2007
7	22	Male	1. Perimembranous VSD (pg: 119 mmHg)	None	Mild	None	None	May 2007
8	24	Male	1. Perimembranous VSD (pg: 100 mmHg) 2. Small PFO ^l	Chromosomal disorder, leukopenia	Mild	None	None	May 2006
9	20	Male	1. Mild pulmonary stenosis (pg: 25 mmHg) 2. Moderate pulmonary insufficiency	None	Mild	None	None	February 2009
10	20	Female	1. Bicuspid aortic valve (mild AR)	Depression	Mild	None	Non-cardiac	December 2009

^aNo. – number; ^bAR – aortic regurgitation; ^cAS – aortic stenosis; ^dTGA – transposition of great arteries; ^eVSD – ventricular septal defect; ^fAV – atrioventricular; ^gPDA – patent ductus arteriosus; ^hRV – right ventricle; ⁱASD – atrial septal defect; ^jpg – peak gradient; ^kLV – left ventricle; ^lPFO – patent foramen ovale.

Table 3: Risk implications of patient- and contextual related factors available at study entry (i.e. baseline variables) for unsuccessful transfer.

Patient-related Factors	Unsuccessful transfer (n = 10)	
	Odds ratio	95% CI
Gender		
Male	1.8	0.5–7.3
ACHD severity		
Moderate vs. Mild	0.2	0–1.2
Severe vs. Mild	0.4	0–3.6
Moderate + Severe vs. Mild	0.2	0–1.1
Contextual-related factors		
Years since pediatric follow-up		
>3 years	1.4	0.4–5.2
Distance to MUMC (km)		
>50	0.4	0–3.6
>50 + >200	0.8	0.2–4.1
>200	7.7	0.7–81.5

transfer is defined as patients seen within 2 years since discharge from the pediatric clinic. The former study only included patients with complex CHD while the current study includes mild, moderate and severe CHD patients. Mackie et al. found that individuals with simple CHD were at a higher risk for loss to follow up when compared to patients with complex CHD. The high transfer rate (96.4%) at McMaster, which includes this high-risk population of mild and moderate CHD patients, indicates the success of McMaster in transferring patients from pediatric cardiology to adult cardiac care. Of note are the limitations of our study. The current study covered a specific period in time, which is between January 2006 and December 2012. This may not reflect our current figures of successful transfer, however, no major changes in the clinical processes of transfer took place over the past few years, making a significant decrease in the figure less likely. It is worth mentioning that this was our first evaluation of transition outcomes conducted at McMaster Children's Hospital using a retrospective chart review, and further, prospective studies are now anticipated to monitor the outcomes of our transitional care over time.

Reflections on cardiac care transfer at McMaster Children's Hospital

Several factors may have played a role in the high rate of successful cardiac care transfer at McMaster Children's Hospital. These may include the following:

a. Early and developmentally appropriate discussions

Early and developmentally appropriate discussions aim to provide the patient and parents with a better understanding of their specific CHD, future expectations, and the importance of continuing with the adult congenital cardiac clinic visits. These discussions may begin as early as 10–12 years of age, as recommended by the American College of Cardiology Task Force and the 2008 ACC/AHA guidelines on the Management of Adults with CHD [31]. It is important to highlight that patients with developmental delays/syndromes did not have a particular problem in the transition process as the parents and caregivers were heavily involved in the patient's care and understood the complexity of the patient's heart condition, along with the prognosis in adult life. The parents and caregivers continue to bring them to the ACCC as in their pediatric age.

b. Engaging the patient in their cardiac care

Encouraging patients to take a proactive role in their cardiac care is an important strategy implemented by the Pediatric Cardiology service. Foremost, the patient is educated on their condition using simple drawings and easy-to-follow pictures, and simple tablet educational applications. Next, patients are encouraged to share how they cope with CHD with their family members and peers. This is in hope that educating the public will decrease any stigmatization or labels placed on individuals with CHD. Moreover, patients are actively involved in their cardiac health management. For instance, patients are engaged in discussions regarding why a specific treatment method is preferred over the other, why an investigation is required within a given timeframe, and why long-term follow-up is required.

An interesting finding is that during the 3 years prior to the study in 2013 (2010–2013), the follow-up outcomes of patients seem to be more favourable when compared to those who were transferred greater than 3 years prior to the study (2006–2009) (OR 1.4; 95% CI: 0.4–5.2). This could be due to changes introduced in 2009 that increased awareness about the importance of transition in pediatric healthcare, lead by the CanChild research centre which is affiliated with McMaster Children's Hospital.

c. Medical record documentation for the need of follow-up

Documenting the recommendation to follow-up with an adult congenital cardiac clinic is important at every clinic

visit in which this recommendation takes place. This is in keeping with Mackie et al. who discussed that documenting the need to follow-up has a protective role against the loss of follow-up [13]. However, our current study found 9 of the 10 patients who were lost to follow-up had documented recommendation to do so. Therefore, it is important to apply other means to reassure successful transition even when the need to follow-up has been documented.

d. Transition pamphlet

At the last pediatric cardiology clinic appointment, patients are given a transition pamphlet regarding their transition to the ACCC. This pamphlet (Supplemental Figure 1) includes important instructions and information about the adult program, its importance, and how to reach and communicate with the clinic. Please note that the contact information of the ACCC staff has been removed from Supplemental Figure 1. In addition, a transition pamphlet is also sent to the patients by the ACCC immediately after receipt of the referral so that the patient is not lost to follow-up. Similar resources provided by the pediatric and adult congenital cardiac services ensures that there is no gap in knowledge and that the patient is comfortable during the transfer process.

e. Early adult congenital cardiac clinic follow-up and reminder call

The first adult congenital cardiac clinic appointment at MUMC is usually fixed to be within 1 year of discharge from pediatric cardiac care, regardless of the severity of the lesion. Although some patients are followed less frequently with the pediatric cardiac clinics, they are given an earlier appointment with the ACCC in order to facilitate successful transfer and to avoid losing patients due to change of address, leaving home for school, etc.

Patients are given a reminder call before their first ACCC appointment. If no answer was obtained a second call is made at a later time. This is to ensure that the patient and/or their parents are aware of the date, time and location of the appointment. It is worth noting that the ACCC at McMaster University Medical Centre has a dedicated nurse practitioner who corresponds with new patients to ensure successful follow-up. When patients miss their appointment, a mailing letter is sent and if we are unable to contact the patient via telephone more than twice, their GP is contacted.

f. Proximity of the adult congenital cardiac clinic

The proximity of the adult congenital cardiac clinic to the patient's residence may be a critical variable in the successful transfer of care. As evident in this study, more than half of the patients (56.6%) who were under the care of the pediatric cardiology program lived within 50 kilometers of MUMC. Similarly, most patients (56.9%) who's care was successfully transferred were living within the same distance. Overall, there was potentially a 7.7-fold increased risk for those who live >200 km from the hospital (OR 7.7; 95% CI 0.7–81.5) to be lost to follow-up, indicating that distance could be a barrier for patients to attend the ACCC though it did not reach statistical significance due to the wide CI.

Furthermore, the proximity of the pediatric and adult congenital cardiac clinics to each other may be another correlate of the successful transfer seen at McMaster Children's Hospital, as both clinics are located at the MUMC. This makes it easier for the patient to follow-up with the ACCC, as they would be familiar with the building environment, parking, it's facilities, and medical diagnostic units, which are the same for many pediatric and adult procedures such as X-ray, EKG, echocardiogram, etc.

Predictors of unsuccessful transfer of cardiac care at McMaster Children's Hospital

In the current study, although significant conclusions could not be established, male patients (OR 1.8, 95% CI 0.5–7.3) and patients travelling greater than 200 km to the hospital (OR 7.7, 95% CI 0.7–81.5) were potentially at a higher risk for loss to follow-up. Goossens et al. also found that male gender (OR: 1.80; 95% CI: 1.02–3.17) was a predictor of patients who were lost to follow-up with adult congenital cardiac care [32]. Our study found that moderate and severe CHD could potentially be a protective factor against loss to follow up when compared to mild CHD (OR 0.2; 95% CI: 0–1.1). This is in line with findings reported by Mackie et al., where they found that patients with a simple shunt lesion have a greater risk for unsuccessful follow-up when compared to patients with complex/severe lesions. It is important to note that patients with mild CHD will be more likely to seek cardiac care from a community cardiologist rather than an adult congenital cardiac clinic [32]. This maybe the case with the patient population in this study as 8 out of the 10 patients who were lost to follow up had mild CHD.

Next steps in improving transitional care

To promote smooth transition and a successful transfer, we need to obtain comprehensive insights about patients' transition readiness, or the ability to self-manage their own health. Since our retrospective chart review, we have implemented the TRANSITION-Q [31] and MyTransition app [27] which were developed by our partner, CanChild research institute. Further studies comparing the transfer processes and outcomes between sites, cities, and countries for congenital heart disease, along with other chronic health conditions are recommended. Recently, Mackie et al.'s review focused on the state of transfer and transition in CHD in Canada and proposed a transition curriculum aimed at CHD education and self-management and self-advocacy skills development [33]. Their findings along with future studies will help to identify best practices and unique patient- and context-related factors influencing successful transfer between pediatric and adult health care settings. Subsequently, this will enable clinicians to develop strategies to achieve improved and sustainable transition outcomes for the patient and their family.

Recommendations

- A. Have regular, early, and developmentally appropriate discussions about the importance of continuity of cardiac care with patients and parents, if patients are eligible for transfer to adult congenital cardiac care.
- B. Improve the patient and parent's understanding of their form of CHD and encourage the patient to take a proactive role in their cardiac care.
- C. Ensure that the transfer of cardiac care occurs in a smooth, sensitive manner.
- D. Standardize the referring process to avoid missing referrals.
- E. Consider a pre-transfer visit to the adult clinic (if not in the same facility) to familiarize patients and their families with the new environment. This might include meeting the nurse practitioner in the adult clinic (if available) and a brief tour of the clinic and diagnostic areas to ease the transition process and facilitate successful transfer.
- F. Conduct further studies to better understand the predictors of unsuccessful transfer to adult congenital cardiac care.

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Ethical approval: Research involving human subjects complied with all relevant national regulations, institutional policies and is in accordance with the tenets of the Helsinki Declaration (as revised in 2013). Ethical board approval was obtained from Hamilton Integrated Research Ethics Board (HiREB) before conducting the study.

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