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Review

Transition and Transfer From Pediatric to Adult Congenital Heart Disease Care in Canada: Call For Strategic Implementation

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ABSTRACT

Dramatic increases in survival to adulthood for persons born with congenital heart disease (CHD) have led rise to a corresponding need to provide age-appropriate and developmentally appropriate care across the lifespan. Health care transition is a multidimensional process that ideally begins in early adolescence in the pediatric setting and continues through young adulthood with input from both pediatric and adult CHD providers. Preparation for transition includes the fostering of adolescents' knowledge of their CHD and of self-management and self-advocacy skills needed for lifelong management of chronic disease. Transfer is the event in time when a patient's care and ownership of health records is taken over by the adult health care team; this is just one element of the broader transition process.

RÉSUMÉ

L'augmentation spectaculaire de la survie jusqu'à l'âge adulte des personnes nées avec une cardiopathie congénitale a entraîné une hausse correspondante de la nécessité d'offrir à ces patients des soins appropriés à leur âge et à leur stade de développement tout au long de leur vie. La transition des soins de santé est un processus multidimensionnel qui commence idéalement au début de l'adolescence dans le contexte pédiatrique et se poursuit durant le passage à l'âge adulte, et auquel participent les dispensateurs de soins spécialisés en cardiopathie congénitale des secteurs des services aux enfants et aux adultes. La préparation en vue de cette transition consiste à éduquer les adolescents à propos de leur cardiopathie congénitale et à les aider à acquérir les compétences nécessaires pour être autonomes et

With dramatic increases in survival to adulthood for individuals born with congenital heart disease (CHD) comes a corresponding need to provide age-appropriate and developmentally appropriate care across the lifespan.[1-3] *Transition* has been defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems."[3] Transition includes, but is not limited to, the *transfer* from pediatric to adult care, which is mandated to occur at the age of 18 throughout much of Canada. Whereas transition is a lengthy process ideally beginning by the age of 12 or 13 years and continuing through a patient's mid-20s,[1,4,5] transfer is a single point in time, when a patient and his or her medical records move from pediatric to adult providers. Despite strong disease-generic position statements from many organizations, including the Canadian Association of Paediatric Health Centres (renamed Children's Healthcare Canada in 2018),[3,6,7] implementation remains low. Although Canada's model of universal health care provides the opportunity for provincial oversight of health care coordination including transition services, barriers to effective transition and transfer of care in Canada include insufficient resources and system factors; a summary of determinants of successful transition and transfer is presented in Table 1. These underscore the complexity involved in providing interdisciplinary transition care across pediatric and adult care settings. Within this review, from a largely Canadian perspective, we summarize current evidence, offer perspectives from multiple

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Transfer typically occurs by age 18 throughout much of Canada. Successful transition is a shared responsibility, requiring engaged pediatric and adult providers and partnership with both young adults and their parents, all of whom may struggle with this process. An interdisciplinary approach to transition is recommended, given that health care transition is a complex process that occurs within the broader context of young adults' lives. This review summarizes existing evidence regarding transition and transfer, offers perspectives from multiple stakeholders, and proposes a transition curriculum of development of CHD education and self-management and self-advocacy skills. Specific recommendations to improve implementation of transition and transfer care within the Canadian context are provided. This review sheds light on the current capacity and challenges of adult CHD providers and proposes directions to move this field forward.

s'autoreprésenter afin d'assurer la prise en charge de leur maladie chronique tout au long de leur vie. Le transfert s'entend du moment où les soins et le dossier de santé du patient sont pris en charge par l'équipe des soins de santé aux adultes; il ne s'agit que d'une étape du processus global de transition. Presque partout au Canada, ce transfert survient habituellement lorsque le patient atteint l'âge de 18 ans. La réussite de la transition est une responsabilité partagée, qui incombe aussi bien aux dispensateurs de soins aux enfants et aux adultes qu'aux jeunes adultes et à leurs parents; tous ces intervenants sont susceptibles d'éprouver des difficultés à l'égard du processus. Nous recommandons l'adoption d'une approche interdisciplinaire, compte tenu du fait que la transition des soins de santé est un processus complexe qui doit s'intégrer au contexte élargi de la vie des jeunes adultes. Nous présentons un résumé des données probantes actuelles sur la transition et le transfert des soins ainsi que les points de vue de différents intervenants, et proposons la mise en œuvre, dans le cadre de la transition, d'un programme d'éducation en matière de cardiopathie congénitale et de perfectionnement des compétences nécessaires aux patients pour être autonomes et s'autoreprésenter. Nous formulons également des recommandations particulières pour améliorer l'exécution de la transition et le transfert des soins dans le contexte canadien. L'article jette la lumière sur les capacités actuelles des dispensateurs de soins aux adultes atteints d'une cardiopathie congénitale et les défis auxquels ils font face, et propose des orientations pour faire avancer les choses.

stakeholders in the transition process, and propose implementation recommendations to improve transition and transfer.

Evolution of Congenital Heart Disease Care

Major advances in the management of children with CHD have evolved over the past 5 decades. As a result, more than 90% of children reach adulthood,[8] and the population of adolescents and young adults with CHD is growing exponentially.[9] Data from the Québec Congenital Heart Disease database identified a 55% increase in the prevalence of severe CHD among adults between 2000 and 2010.[9] This is a remarkable success story. However, this emerging "survivor" population has complex needs. CHD is very heterogeneous with a wide range of clinical outcomes, both across and within diagnostic categories. Although survival of patients with isolated simple defects nears that of the general population, patients with disease of moderate or complex CHD are at risk of substantial cardiac and noncardiac morbidity and premature mortality.[10-14] Further, irrespective of disease complexity, adults with CHD have a higher rate of mental health challenges including depression and anxiety,[15] which have an important impact on health-related quality of life.[16] As a result, this population requires significant health care resources to ensure effective management of chronic disease.[17-19]

Pediatric providers have a vested interest in the long-term well-being of their patients that extends well beyond the age at which care is typically transferred to experts in adult CHD (ACHD). Management decisions consider the long-term outcomes of the child or adolescent who will one day become an independent adult. Examples include decision making related to surgical intervention for aortic valve disease regarding the long-term implications of a mechanical aortic valve vs Ross procedure, or adoption of perioperative strategies to mitigate the effects of infant heart surgery on long-term neurodevelopmental outcomes. However, pediatric cardiologists need to consider not only hemodynamic burden and cardiovascular-specific morbidity. In conjunction with nurses and other allied health professionals, pediatric cardiologists have the obligation to help prepare adolescents as they age into the health care system.

Why Does Transition Matter?

The process of transition, when done well, results in young adults who have entered and engaged with the adult-oriented health care system in a timely manner following graduation from a pediatric program without a lapse in care and without avoidable intervening complications. Successful transition is demonstrated by patients who are armed with knowledge of their health condition and the self-management and self-advocacy skills needed to be active partners in their health care management. Unfortunately, transition often falls short of these goals. For example, many young Canadian adults fail to attend an ACHD centre after aging out of pediatric care.[20,21] Adolescents and young adults with CHD may have a false sense of being "cured," which contributes to lapses between pediatric and adult cardiology care and increasing admissions via the emergency room.[19,22,23] Such lapses predispose to delayed recognition of late cardiac complications.[23] The population of adolescent and young adult CHD survivors is increasing exponentially, and they remain at risk of long-term complications.[12,24,25] These factors speak to the urgency of implementing practical, evidence-based interventions that will optimize pediatric to adult health care transition and retention in specialized CHD care. Research using the Québec

Table 1. Determinants of successful transition or transfer

Determinants		Examples
Health care system	Access to care	Limited availability of ACHD providers
		Wait lists for primary care and CHD care
		Geographic distance to CHD program
	External environment	Access to shared electronic medical record
		Provincial/institutional prioritization of transition-focused care
		CHD program's human resources, funding and clinic space to provide transition-focused education and services
Health care providers	CHD specialists	Quality of patient's relationship with pediatric cardiology providers
		Quality of patient's relationship with ACHD providers
	Other providers	Quality and consistency of relationship with primary care provider
		Quality and consistency of relationship with dentist
		Quality of relationships with other subspecialists
Family/community	Social support	Parental/caregiver support
		Parental/caregiver commitment to supporting transition and increasing adolescent independence
		Sibling/friend/partner support
		Support of other adults within the community (eg, teachers, coaches)
	Attachment	Attachment between parents/caregivers and pediatric providers
		Attachment between family and ACHD providers
Patient	Medical/treatment history	Severity of CHD lesion
		Surgical/catheterization/hospitalization history
	Neurodevelopmental factors	History of neurodevelopmental deficits/disabilities
		Educational attainment/expectations
		Employment expectations
	Psychosocial factors	Mental health
		Resilience
		Substance use
		Co-occurring life transitions (eg, romantic relationships, education, employment) that might be perceived as greater priorities
	Resources	Family socioeconomic status
		Health insurance
		Ability to travel to and attend outpatient clinic appointments
	Personal health beliefs and practices	Perceived benefit of lifelong specialized care
		Perceived likelihood of potential cardiac and non-cardiac complications
		Confidence in new (ACHD) care team
		Attendance at scheduled outpatient clinic visits
		Adherence with medications, endocarditis prophylaxis, healthy lifestyle behaviours, and so forth

ACHD, adult congenital heart disease; CHD, congenital heart disease.

CHD database demonstrated a significant increase in referrals to specialized ACHD centres following the introduction of Canadian ACHD clinical guidelines.[26] Moreover, referral to specialized ACHD care was independently associated with a significant mortality reduction, thus supporting a model of specialized care for all patients with ACHD.

Although CHD is the focus of this review, many elements of the transition process and transfer event are common to a range of pediatric-onset chronic conditions including cystic fibrosis, diabetes, and rheumatologic conditions.[7] Across diagnoses, within the "Triple Aim" framework, attention is directed toward improving the experience of care (eg, patient satisfaction), improving population health (eg, patient-reported outcomes and self-care skills), and reducing the cost of health care.[7,27,28] A population-based diabetes cohort study conducted in Ontario, Canada revealed that gaps in care during the transition age were common and associated with adverse outcomes (ketoacidosis or death).[29] Among 33 transition intervention studies included in a 2014 systematic review, only 3 studies examined costs,[28] including a Canadian study that demonstrated the economic feasibility of a transition clinic for adolescent renal transplant recipients.[30] There are, nonetheless, some key disease-specific characteristics that must be acknowledged. Unlike some other pediatric-onset health conditions, physical symptoms and medications may not be part of the daily lives of young people with CHD. Accordingly, patients who are asymptomatic might underestimate the severity of their CHD and may question the need for ongoing specialized ACHD care. However, CHD, unlike many other chronic conditions, requires highly invasive procedures for some patients. Canadian data demonstrate that a catheter intervention in the preceding 5 years, for example, is protective from a lapse in care[31], as is a history of having had 2 or more cardiovascular surgeries.[20]

Transfer: How Many Survivors Graduate to ACHD Care Each Year?

The prevalence of CHD among children is 13.11 per 1000 children, based on population-level data from Québec.[9] As of 2016, there were 7 million children in Canada below 18 years of age, translating into approximately 92,000 living with CHD. With respect to 17-year-olds who are imminently entering the adult health care system, there were 400,000 in Canada in 2016,[32] of whom 5200 can be expected to have CHD. It is recommended that all CHD patients be seen at least once in an ACHD centre;[33] all patients with severe CHD and a significant proportion of those with moderate and even mild CHD require surveillance.[12] Thus, the annual intake of patients being transferred to ACHD providers is substantial.

Canada's government-funded universal health-insurance system offers some advantages with respect to providing comprehensive transition care. Pediatric programs need not rely on third-party payers for remuneration for delivering transition interventions, and young adult patients are able to access care, regardless of employment and/or insurance status. However, there are also challenges with the Canadian system. For example, a study from the field of cystic fibrosis revealed that although access to care may be universal, the availability and quality of transition programs varies among institutions.[34] Long wait lists may result in delays to a first ACHD appointment or to interventional procedures as programs struggle to meet the growing demand of patients, and limited budgets and human resources may result in lack of personnel to deliver transition-related care.[35] The geography of Canada results in significant travel times and costs for patients living in remote communities, and distance from ACHD centres can be a barrier to attending appointments.[36] Nonetheless, the growth of pediatric hospital-based transition programs and transition research across the country attests to the opportunities for further development of health care transition in Canada.

Transition

Developmental tasks of adolescents and young adults: where does transition fit in?

The process of transition continues throughout adolescence and following transfer to adult care (Fig. 1). This covers a wide range of developmental stages, as the average 12-year-old is quite different from the typical 15-year-old, who is, in turn, unlike 18- to 25-year-olds. In addition, there exists significant heterogeneity within individuals of a certain age. Although one typically thinks of chronological age regarding transfer of care (at the age of 18 in most of Canada), transition should be personalized, in accordance with a patient's chronological age as well as developmental stage and abilities.[5,37]

From a developmental perspective, adolescence is associated with exploration of social roles and identity formation; this is often accompanied, unfortunately, with an increase in risk-taking behaviours. It is important for health providers to remain mindful that, although we may be most focused on healthcare transition of adolescents and young adults with CHD, patients themselves are experiencing transition in a much broader context. Examples include changes and decision making with respect to friendships, romantic relationships, living situations, and academic and career decisions. When speaking with adolescents and young adults, therefore, providers are encouraged to communicate in a way that acknowledges the whole person and the multiple transitions that may be taking place in their lives.

A successful transition outcome has been defined as "achievement of both continuity of optimal health care across the lifespan and the knowledge and self-management skills to assume maximal responsibility of their health care management and live as full and independent lives as possible."[38] Yet, there remain major challenges regarding how to evaluate transition readiness and offer transition-focused care for patients who do not have the ability to one day assume primary responsibility for their health care.[38] Patients with significant neurodevelopmental deficits are typically excluded from transition research studies. However, there is significant variability across neurodevelopmental deficits and disabilities, and the goal remains to maximize patient knowledge and self-management skills to the highest degree possible for each individual patient. This can likely best be achieved within a proactive and systems approach that engages family physicians.[39] In the CHD and primary care pediatric settings, to respect adolescents' privacy and also engage their developmental abilities in the domains of knowledge and self-management skills, it is advised to develop a programmatic policy in which providers speak with adolescents alone (ie, without parents in the room), for part of each clinic appointment.[5,40]

The transition process continues during the first few years following transfer to the adult-care setting. Patients between the ages of 18 and 25 have been referred to as "emerging adults," in that they are at a stage between adolescence and full adulthood; here, the focus is decision making and accepting responsibility.[41] These foci are consistent with expectations in the adult setting, in which the shift from family-centred to patient-centred care implies that patients are "expected" to take primary responsibility for health care decision making. It might be frustrating for patients, parents, and providers when there is a mismatch between provider expectations and patient abilities and comfort levels. Increasingly important are the perceptions and expectations of patients who are clearly the key stakeholders in the transition process; a Canadian study of 21 emerging adults with CHD revealed that positive impressions of ACHD care included increasing autonomy and responsibility as well as the opportunity to discuss adult-focused health issues (eg, family planning).[42]

Transition interventions: what is the evidence?

The Canadian Association of Pediatric Health Centers, American Heart Association, and other organizations have published position statements on transition, with suggested transition practices.[1,4,6,7] However, there are relatively few published outcome data related to transition interventions. This may reflect the complex, multifaceted nature of transition and/or the challenges of engaging and retaining adolescents in research. To date, transition efforts have generally targeted 1 or more of the following: knowledge, self-management skills, and self-advocacy.

Health knowledge. Two Canadian studies have documented important knowledge gaps among adults with CHD with respect to their heart, highlighting 1 aspect of adolescent CHD care that has clear potential for improvement (Table 2).[43,44] Adolescents with CHD who are knowledgeable about their hearts are more comfortable communicating directly with health care providers, rather than having their parents do so.[45] Children as young as 8 to 11 years of age are typically ready to start learning about their cardiac conditions through pictures and simple language, to learn about symptoms that may warrant immediate medical attention, and to learn about the names and schedule of their medications. Providers should speak directly with children in this age range, inquiring about symptoms and encouraging questions, and should encourage parents to discuss these topics with their

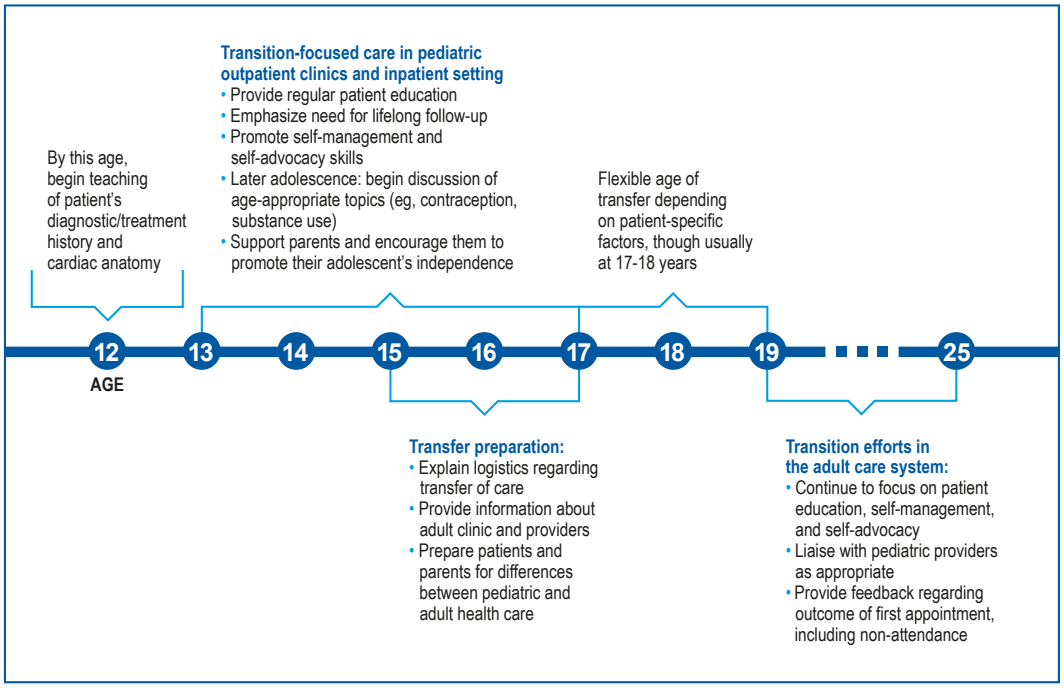

Figure 1. Suggested timeline for transition and transfer.

children. In early adolescence, teens are encouraged to be able to explain their medical condition to others, learn about the rationale for tests and procedures, understand the purpose of medications they take, and learn about the broader lifestyle implications of living with CHD.

A 2016 Cochrane review considered studies that aimed to improve the transition of care from pediatric to adult services.[46] This review identified only 4 clinical trials of transition interventions, of which 1 was specific to pediatric heart disease. This Canadian publication, the **C**ongenital **H**eart **A**dolescents **P**articipating in **T**ransition **E**valuation **R**esearch (CHAPTER) 1 study, evaluated the impact of a structured, nurse-led, 1-on-1 teaching program for adolescents aged 15 to 17.[47] The intervention took approximately 1 hour and included creation of a MyHealth passport[48] (a portable summary of the pertinent diagnoses and previous interventions, name, dose, and rationale of medications) and a review of the participant's cardiac anatomy including previous interventions. This study demonstrated a significant increase in CHD knowledge in the intervention group that was sustained to 6 months postintervention,[47] perhaps because the intervention participants had the opportunity to refer to (and show family/friends) their MyHealth passport as needed, allowing them to review and retain the information they had acquired during the teaching session.

Table 2. Elements of a CHD education transition curriculum

Explain the importance of transition
Emphasize the need for lifelong specialized ACHD care
Create a portable health summary (eg, MyHealth passport) with patient, including
- name of cardiac condition
- previous cardiac interventions
- name of medications
- need for endocarditis prophylaxis (Yes/No)
- names and contact details of health providers (CHD and primary care)
Review diagram of cardiac anatomy (patient-specific)
Discuss potential future cardiac and noncardiac complications (patient-specific)
Discuss lifestyle issues as they relate to CHD such as considerations for educational or vocational planning (if any), physical activity, smoking, substance use, and family planning
Provide contact names and location of local ACHD cardiologists
Introduce patient to relevant websites such as iHeartChange, Canadian Congenital Heart Alliance

ACHD, adult congenital heart disease; CHD, congenital heart disease.

The CHAPTER 2 Study, a larger, 2-centre Canadian study of a 2-session nurse-led intervention program demonstrated that improved knowledge of the health condition can be sustained at least until 18 months postenrollment.[49] Participants in the intervention group had a lower likelihood of a delay in obtaining ACHD care, perhaps because they had a greater awareness of the need for lifelong cardiology follow-up and were more likely to respond to support staff and/or attend their first adult cardiology appointment. Interventions in both the CHAPTER 1 and 2 studies were provided by cardiology nurses—rather than nurse practitioners—to reduce costs and improve generalizability to other programs.

Although there are no published intervention studies focused on children or adolescents younger than15 years of age, transition readiness is higher among young adolescents who are knowledgeable about their heart conditions.[50] Parent knowledge of the medical condition also correlates positively with patient knowledge,[50] although many parents are not able to provide CHD education to their child. Accordingly, young adolescent transition programs should include parental involvement.

Self-management. Self-management of a chronic health condition refers to the ability to complete tasks such as

arranging medical appointments, filling prescriptions, and communicating directly and making decisions with health providers (Table 3). Self-management can be measured in adolescents using the Transition Readiness Assessment Questionnaire (TRAQ),[51] or the more recently published TRANSITION-Q, a Canadian questionnaire consisting of 14 questions that takes only approximately 2 minutes to complete.[52] Self-management skills improve with increasing age, but—more importantly—improve in response to nurse-led interventions. Both the CHAPTER 1 and 2 studies demonstrated a significant increase in self-management skills in the intervention group that were sustained over time. However, it is worth noting that the CHAPTER 1 intervention focused on CHD knowledge rather than traditional self-management skills, which is consistent with a previous report that well-informed patients are more confident in managing their health conditions.[45] The CHAPTER 2 intervention included a 1-hour session focused on self-management skills.[53] Although there are no data on the long-term impact of self-management skills on clinical endpoints (eg, incidence of late cardiac complications), these behaviours have face validity; without these skills, patients fail to engage with the health care system.

Self-management skills may be influenced by interventions other than clinic-based transition teaching. iHeartChange (iheartchange.org) is a publicly available website, developed in Toronto, that focuses on the needs of young adults with CHD. Content includes medical information, lifestyle information (eg, smoking, healthy eating, exercise, relationships, substance use), coping (managing stress, anxiety, and depression), "taking charge of your health" (managing medical records, advance care planning, etc), and other topics.[54] Online resources, such as MyHealth Passport and iHeartChange, may help foster patient knowledge and self-management skills yet should not be considered sufficient as transition interventions; they can augment—rather than replace—individualized patient-provider transition-focused care. Patient engagement and partnership is critical in the transition process.[55]

Self-advocacy. Self-advocacy refers to skills needed for communication with the health care team, managing activities of daily living, and making effective use of community resources (Table 3).[51] Although intuitively important for persons living with chronic health conditions, there are no studies, to our knowledge, that have focused primarily on self-advocacy skills among adolescents or young adults transitioning to adult health care. This is an opportunity for future investigation.

Table 3. Elements of a self-management and self-advocacy transition curriculum

The concepts of self-management and self-advocacy and their relevance to health
How and when to use a portable health summary (eg, MyHealth passport)
How to contact care providers
When and how to access emergency health care
How to schedule clinic appointments
How to request prescription refills
How to maintain health records
Strategies for communicating with health care providers (consider role playing)
When and how to access mental health services
When and how to access student health services (if applicable)
SMART goal setting (Specific, Measurable, Attainable, Relevant, Timely)

Scope of published transition interventions. A 2017 systematic review summarized programs designed to facilitate transition and transfer to adult care, mostly in single-disease groups such as diabetes or kidney transplant.[56] Included studies evaluated access to a dedicated transition coordinator/system navigator; joint pediatric and adult provider-run clinics; young adult clinics; group mentoring programs; access to web and text-based education programs; tours of the adult-oriented health care facility, combined with information sessions; and others.[56] However, the methodologic rigor of many transition intervention studies is weak, with only 7 of 43 (16%) having an overall methodology rating of "strong,"[56] and only 4 studies met criteria for inclusion in a 2014 Cochrane review.[46] Accordingly, there is considerable opportunity for rigourous evaluation of models of transitional care, ideally with an emphasis on the impact on clinical outcomes.

Transfer

Structure/organization of ACHD specialty care in Canada

Canada has a rich history in the field of specialized ACHD care. One of the first ACHD programs in the world was established in Toronto in 1959. In 1991, Canada established one of the first national networks for ACHD care, the Canadian Adult Congenital Heart (CACH) Network (www.cachnet.org), which linked ACHD cardiologists across the country. The CACH Network, comprising 15 programs, has led to specialization and concentration of complex ACHD care in a few regional centres, with more routine care devolved to local providers.

As the population of adult patients has grown, the population of care providers with appropriate training and skills has struggled to keep up. A 2007 survey investigated the structure and process measures of quality of care across the CACH Network centres.[35] Of the approximately 100,000 adults with CHD in Canada at that time, less than 25% (21,879) were active patients at one of the CACH Network programs, although approximately 50% require ongoing care at ACHD centres.[35] Although the data are now more than a decade old, despite a national and coordinated approach to ACHD care, the finding that a substantial proportion of Canadian adults with CHD do not access specialized services likely persists. This is alarming, given data from the Québec Congenital Heart Disease database that demonstrated a significant reduction in expected adult patient mortality following an increase in referral rates to specialized ACHD centres.[26] A subsequent investigation of ACHD care in Canada, published in 2019, confirmed that there remains a disproportionate ratio of resources to patients.[57] This is not a Canada-specific problem, as the paucity of ACHD physicians has also been documented in the United States.[58] In both Canada and the United States, therefore, the lack of ACHD providers means that many adolescents and young adults will be followed by pediatric providers (which is certainly preferable to an absence from CHD care altogether). It is unlikely

that this issue will be resolved until the shortage of ACHD services is addressed.

Lapses in care

Lapses between pediatric and ACHD care predispose to late detection of new or evolving cardiac complications and the need for urgent reintervention.[23] The absence of symptoms may imply to patients that all is well,[59] but evolving right ventricular volume overload in tetralogy of Fallot, for example, may go undetected until there is irreversible right ventricular dysfunction. Further, adult patients are at increased risk for noncardiac comorbidities for which close monitoring by CHD providers is warranted.[10] Pediatric and adult cardiologists cannot effectively screen for these complications when patients fail to attend outpatient care.

Low rates of loss to follow-up have been achieved in some jurisdictions. Belgian data showed that only 7.3% were not in follow-up, notably male patients and those with no history of heart surgery, though Belgium is a small, densely populated country with universal health care coverage,[60] and pediatric and adult CHD providers in that study were co-located in the same building. A single-site American study found that only 18% of young adult patients previously seen between the ages of 14 and 18 were no longer in cardiology care, although this study evaluated a predominantly Caucasian population and was subject to selection bias, as adolescents never seen between 14 and 18 years of age were excluded.[61] In contrast, a multicentre American cohort reported that 42% of patients with ACHD had lapses in care of more than 3 years; those with mild lesions were at highest risk.[22] Most recently, it was reported that less than 20% of patients in Georgia, in the United States, transferred to ACHD programs, with distance to referral centre identified as a risk factor.[36]

Lapsed cardiology follow-up is not unique to the time of transfer from pediatric to adult care. Reid and colleagues in Toronto wrote a seminal paper that was the first to highlight the magnitude of CHD loss to follow-up within the Canadian health care system.[20] Among 360 patients who had been seen at SickKids, 170 (47%) were seen at a Canadian ACHD centre by age 22 and thus were considered to have had a successful transfer. This publication is often used to suggest that only half of adolescents with CHD successfully transferred from SickKids to a Canadian ACHD centre. However, many patients did not have follow-up at SickKids during adolescence, and, in fact, 22% of the cohort had not been seen at SickKids after they turned 10 years old. Thus, an important message from this study is that many lapses in care begin before the age of transfer (~18 years). This is consistent with population data from Québec, which illustrated that, among children with CHD, loss to follow-up is prevalent within the pediatric age range. Even among those with severe lesions, 21% were not seen after the 18th birthday.[21] The great majority of Québec patients were still seeing primary care physicians, which implies that there may be a lack of awareness of the need for cardiology follow-up within the broader medical community. Risk factors for loss to follow-up included male sex and having nonsevere lesions.

A subsequent study from Alberta reported that risk factors for loss to follow-up >3 years among children or adults with CHD included a lack of patient and parent awareness of the importance of follow-up and lower socioeconomic status.[31] These data emphasize the need for pediatric cardiology programs to be vigilant about maintaining contact with patients. This can be achieved by discussing the rationale for follow-up with patients and families beginning at an early age, proactively scheduling appointments (rather than relying on patients or parents to do so), and promptly contacting patients and their primary care providers (eg, family physician, pediatrician) when patients fail to attend the cardiology clinic.

Strategies to promote successful transfer in Canada

Successful transfer requires strong communication and collaboration between pediatric and adult providers and an understanding of the barriers to care as summarized here. Within individual cities, a transition working group that includes health care providers from pediatric and adult programs can facilitate communication and dissemination of transition plans.[54] A 2015 systematic review that summarized experiences and outcomes for CHD transition identified several factors associated with retention (rather than lapses) in care.[62] Of the 4 factors, the first 3 may be modifiable by pediatric cardiology teams: belief that specialized CHD care is necessary, patient attendance at pediatric clinic appointments without parents, pediatric referral to an ACHD centre, and poorer health status. Thus, within an educational curriculum targeting adolescents and young adults with moderate or complex CHD, the importance of lifelong specialized cardiac care must be included. Further, at the time of transfer, pediatric CHD teams should provide written documentation to patients regarding ACHD follow-up, including contact information as well as details about the location, driving options, public transportation, and parking. Expectations for the recommended date of the first AHCD clinic appointment should also be provided.[54]

Predictors of successful transfer in the study by Reid et al. included higher number of pediatric surgeries, older age at their final visit to SickKids, documentation in the medical chart of the need for ACHD follow-up, patient beliefs that ACHD care should be at an ACHD centre, not using substances, and attending cardiology appointments without parents or siblings.[20] This paper therefore provides valuable insight into strategies that we might reasonably hypothesize would improve the rate of transfer (Table 4). Importantly, attending appointments without parents likely reflects that adolescent patients who are knowledgeable about their heart conditions are more likely to feel comfortable communicating directly with health care providers, consistent with interview data subsequently published by the SickKids team.[45]

Although many guidelines support a flexible age for transfer (eg, 18 to 21 years),[4] this is not possible in most Canadian jurisdictions. The mandatory transfer age of 18 for inpatient care does have the benefit, in theory, of planning ahead for a final CHD visit before a patient's 18th birthday. One of the "critical first steps" for successful transition has been identified as the preparation of a health care transition plan, beginning by the time a patient is 14 years old, that describes necessary adult-oriented health services and who will provide them.[6] Therefore, pediatric providers ought not to wait until the final pediatric visit before discussing transfer of

Table 4. Suggested strategies to improve transition and transfer

Domain	Setting	Recommendation
Transition	Pediatric	Identify a transition champion to facilitate and evaluate transition efforts.[30]
		By early adolescence, inform patients and parents/guardians that the patient will be transferred to ACHD care by age 18 (or age of transfer in that jurisdiction).
		Ensure that patients and parents know that specialized CHD care throughout the lifespan is necessary.[31]
		Beginning in early adolescence, and as developmentally appropriate, provide an individualized and structured approach to education about their CHD, including associated lifestyle information, and development of self-management skills, progressing at the youth's pace. Include parents of younger adolescents in transition teaching.[47,50]
		In conjunction with patients, create a portable health summary (eg, www.sickkids.ca/myhealthpassport).[47,48]
		Provide transition education in conjunction with cardiology clinic appointments.
		Consider the use of a transition readiness survey to periodically evaluate for potential gaps in knowledge and/or self-management abilities.
		Fully engage parents in the transition process, and explain the goals and rationale of fostering their child's independence and addressing potential challenges for overprotection.
		Establish a practice of speaking with adolescent patients on their own for a portion of every clinic visit (as developmentally appropriate).
		Ask patients and parents whether they are satisfied with the amount of transition education they are receiving; tailor future education accordingly.[64]
	Adult	Identify a transition champion to facilitate and evaluate transition efforts.[30]
		Recognize that patient education is an ongoing process, with an emerging focus on adult issues, such as employment, insurance, and family planning.[1-3,6,7]
		Ask patients whether they are satisfied with the amount of CHD-related information they have received; tailor future education accordingly.[64]
		Provide information on ACHD patient organizations (eg, Canadian Congenital Heart Alliance).[47]
Transfer	Pediatric	Ensure the transfer policy (eg, age at transfer) is known to patients and parents.
		Ask patients and parents whether they have concerns about transferring to ACHD care.[65,66]
		If medically feasible, plan transfer to adult care during a time of relative clinical stability.
		Provide clear documentation of referral to ACHD centre to patients and parents including contact information and location of ACHD clinic.
		Provide a comprehensive transfer summary for the adult care team.
		Establish a regular schedule (eg, quarterly) of following up on patients referred to the ACHD team to ensure first appointments are scheduled (with the aim of reducing lapses in care).
	Adult	Maintain a database of transferred patients to ensure timely scheduling of first visit (with the aim of reducing lapses in care).[54]
		If unable to reach a patient to schedule the initial ACHD clinic visit, inform the pediatric providers who might have more success with contacting the patient, given the historical relationship.
		At the first 1 or 2 clinic visits, prioritize building the new patient-provider relationship to support retention in care.

ACHD, adult congenital heart disease; CHD, congenital heart disease.

care. In some jurisdictions, patients may be followed in the pediatric outpatient setting beyond 18 years, although pediatric hospitalization is not permitted. It is therefore possible that inpatient providers may not have access to patients' most recent outpatient medical records; shared electronic medical records may mitigate this challenge.

When possible, transfer to adult care should occur during a time of relative clinical stability,[5] which may entail planning the timing of anticipated surgeries and catheter-based procedures before transfer and ideally not within the first year following transfer. A comprehensive transfer summary should be provided to the ACHD team, the purposes of which are to support continuity of medical care.[5,54] The transfer document should include all relevant information regarding cardiac diagnoses and history (surgeries and catheter interventions, complications, medication history; recent diagnostic reports; and history of arrhythmias, heart failure, and endocarditis); noncardiac comorbidities; and familial, psychosocial, and developmental factors that might have an impact on health care. Recommendations regarding timing of the first visit in the ACHD clinic are also helpful.

The Patient and Family Perspective

There is significant variability in adolescents' perspectives on the transfer to ACHD care. A feeling of uncertainty, a sense of normality, and a "wait-and-see" approach have all been described.[45,63] A qualitative study of 20 adolescents (aged 16 to 20 years) and 20 adults (aged 21 to 40 years), all with CHD, revealed challenges in making generalizations regarding transition needs.[64] Of the adolescents in this study, half were satisfied with the amount of transition education they had received, and the other half would have preferred to receive more information. There was a similar 50-50 split regarding having vs not having concerns about becoming adults with CHD. Among the interviewed adults in this study, approximately half (11 of 20) were satisfied with the information they had received as adults. Therefore, it seems that the simplest way to know whether patients are satisfied with their CHD-related education and feel prepared for adult care is to ask them.

There are challenges and psychosocial effects of having a child with CHD, and parents are thus deserving of recognition and respect for facing situations that parents of healthy children do not, such as consenting and witnessing their children undergo major open-heart surgeries. It is thus important that pediatric and adult CHD providers support parents as they face the often-difficult task of "letting go" of certain tasks (eg, making medical decisions, scheduling medical appointments, asking questions of health providers). During the transition process, parents benefit from support as they balance fostering their child's independence while at the same time ensuring ongoing medical care, address their own issues regarding overprotection, and prepare to say farewell to the pediatric team who has taken care of their child for up to 18 years.[5]

Most parents are poorly prepared for both transfer and transition of care. Among 500 parents in the United States, only 44% recognized that their child's care would be guided by adult care providers.[65] In Sweden, of 351 parents of adolescents with CHD, most respondents had at least a moderate degree of uncertainty regarding the process of their child's transfer to ACHD care.[66] These findings highlight the importance of integrating parents within the transition process. The aim is for providers and parents to partner in the provision of transition support for adolescents and young adults, with the shared goal of fostering independence and discouraging unnecessary overprotection.

Transition Team Members

Pediatric CHD providers

From early life, a strong, bilateral emotional bond occurs with the pediatric team and the patient and family. In a survey of 291 American pediatric cardiologists, the most frequently endorsed barriers to ACHD care were emotional attachment to the pediatric cardiologist by parents (87%) and patients (86%); provider attachment to patients and families was identified as a barrier by 70% of respondents.[67] It is therefore pivotal that pediatric providers be leaders in the transition process.[1-3,6,7] They initiate both transition and transfer, emphasizing the importance of lifelong cardiac surveillance. Ideally, pediatric providers foster the skills and resources for transition, ensure patient and parent readiness for transfer, identify appropriate ACHD providers, and ensure timely and appropriate transfer of medical records. These tasks require team-based collaboration among cardiologists, nurses, social workers, psychologists, and administrative staff in both pediatric and adult settings.[68] Family physicians are also a key member of the patients' health care team, and for patients without a family physician, the pediatric team needs to provide assistance in obtaining a primary care provider.

Despite best intentions, practical barriers may hinder the establishment and/or maintenance of a transition program. In a busy clinic environment, time constraints can preclude individualized education and discussions about the need for lifelong care. This can be mitigated by addressing a manageable number of topics (1 or 2) at any given clinic visit and making transition care a routine part of outpatient appointments from the age of 12 or 13 onward. Patients and families should be informed in advance that this will happen at the time of appointment scheduling. A transition curriculum adapted to the developmental milestones of the patient can be used to document steps achieved over time. Dedicated time and space for teaching within or near the clinic area will facilitate the successful delivery of a transition curriculum. Whether transition teaching is provided by physicians, nurses, or other professionals may be less important than the providers' enthusiasm for the topic and for working with adolescents. However, clinicians who provide transition teaching on a regular basis likely develop time efficiencies and the expertise needed to identify adolescents needing additional support and teaching. Accordingly, identifying 1 or 2 transition leads within a given program is important in implementing the transition program delivery. The elements of transition curricula outlined in Tables 2 and 3 should be initiated in the pediatric care environment. Table 4 provides key recommendations for transition and transfer in the pediatric clinic.

Institutional support is instrumental in the development of an effective transition program. Generic resources that apply to multiple health conditions across hospital programs such as a website, health passports, and posters have been well described.[54] Generic resources can complement—but not replace—disease-specific, clinic-based transition programs that provide content expertise, familiarity with individual patients and family, and familiarity with adult care providers.

ACHD providers

The ACHD cardiologist should consider the initial clinic visits as a "getting to know each other" meeting rather than an opportunity to change the direction of care. Except for the uncommon situation in which there is a pressing clinical need, the ACHD care team should emphasize like-mindedness and continuity of care and be careful to not undermine the previous clinical care pathway established by the pediatric team. When available, the continuity of surgical providers should be emphasized. Although the adult and pediatric teams may have different approaches to complex decision making, there is rarely a need to rush into new treatment decisions. The elements outlined in Table 2 (CHD knowledge) initiated by the pediatric team should be reviewed and elements summarized in Table 3 (Self-Management and Self-Advocacy) should be emphasized. This can be done with a team approach in a step-wise fashion so as not to overwhelm the patient and family. Nurses play key roles in assessing and further developing the CHD knowledge and self-management skills of young adults.[69] An important component of transition is teaching young adults (and their families) strategies to navigate adult health care environments. This is particularly true for those with multisystem disorders, learning difficulties, or other special needs.

ACHD providers are encouraged to be mindful of family dynamics. As young adults interact with the new team, there will be an unspoken but real repositioning of the team with the family. In adult care, this is very much a realigning of the physician with the patient rather than with the parents. At a time when self-autonomy is key, the changing dynamic to focus the discussion, education, and decision making with the young person needs to be negotiated gently. Although the process might be perceived as challenging for many young adult patients, ACHD providers can reframe this as an empowering and exciting phase of life.

Patients are not the sole targets of education in the adult setting. It is the responsibility of ACHD providers to educate their non-ACHD colleagues, including other medical subspecialists and inpatient providers whom young adult patients are likely to encounter. Themes of this professional education are not limited to the medical care of complex CHD (eg, postoperative care of patients undergoing transplants or Fontan revision surgery), but also to the unique developmental and psychosocial needs of transition-age patients.

Primary care providers

Working collaboratively with CHD specialists, primary care providers are in a unique position to provide care across

the age span and be a consistent presence for young adults as they leave pediatric care and enter the adult-oriented health care system. Primary care providers often have unique insights into broader family dynamics and psychosocial factors that may affect transition. Primary care providers are well positioned to encourage self-management skills in the youth, manage common mental health challenges, and refer to other adult specialists as needed. Primary care providers can also serve a vital role in ensuring successful transfer and retention in ACHD care by monitoring ACHD clinic attendance, particularly the initial visit following graduation from pediatric care. However, this can often be challenging, as there is limited access to primary care providers in many parts of Canada. The integration of primary care providers within the transition process warrants future empirical investigation.[70]

Conclusions and Future Directions

Consistent with the "Triple Aim" framework, CHD transition efforts should focus on the experience of care, improving health outcomes, and reducing health care costs.[7,27,28] For patients and families, successful transition leads to optimal medical outcomes, psychosocial health, and quality of life of young adults, enabling them to be engaged with society to the fullest extent possible. From a health services utilization perspective, this should result in age-appropriate and developmentally appropriate cardiac surveillance without lapses in care as well as the minimization of avoidable ED visits through optimized outpatient care. Transition to ACHD care is a complex, multifaceted process that benefits from an individualized, coordinated, and collaborative process involving adolescents and young adults, their families, and pediatric and adult providers. Despite known barriers and challenges, transition offers a unique set of opportunities, which, if managed wisely, can set the foundations of a highly successful long-term relationship among patients, their disease, and their care providers.

Most transition intervention research has methodologic limitations including single-centre design, short follow-up periods, and lack of a control group. Cost-effectiveness analyses are needed to inform evidence-driven business plans that would support and sustain transition intervention programs. Rigourous, high-quality transition intervention research is feasible, particularly when the research question focuses on 1 specific aspect of an overall intervention program. The presence of a control group is recommended, as this reduces the likelihood of erroneous conclusions that can occur with a simple pre-post design. Long-term studies are needed to evaluate the impact of transition programs on clinical outcomes.

Many Canadian pediatric hospitals have demonstrated leadership and innovation in the development of comprehensive transition programs, and providers in both pediatric and adult health care systems have made important contributions to transition-related topics including lapses in care, transition interventions, and the development of transition readiness tools.[21,48,49,52] Clinicians should continue to advocate for the resources needed to provide high-quality transition care, including personnel and space. For more than 25 years, health care providers working with adolescents have known of the importance of a coordinated transition process. The next phase must be focused on implementation of transition-focused clinical strategies, as the long-term health of CHD survivors will depend, in part, on our ability to ensure continuity of specialized CHD care across their lifespans.

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