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CONGENITAL HEART DISEASE (RA KRASUSKI, SECTION EDITOR)

# Transition of Care in Congenital Heart Disease: Ensuring the Proper Handoff

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**Abstract**

*Background* With great advances in medical and surgical care, most congenital heart disease patients are living in to adulthood and require lifelong surveillance and expert care for adult onset complications. Care lapse and lack of successful transfer from pediatric to adult care put young adults at risk for increased morbidity and premature death. Hence, transition and transfer from pediatric to adult care is a crucial and critical process to provide access to specialized care and lifelong surveillance.

*Purpose of Review* The aim of this article is to describe barriers to successful transition and transfer and to share practical strategies and concepts to overcome these barriers in order to successfully implement a transition program.

*Recent Findings* There are patient-specific, local, and institutional specific barriers to establish a successful transition program which involves many stakeholders. Collaboration of the Pediatric and Adult Congenital Heart Disease programs is paramount; the understanding of the benefit and the need of a structured transition program, dedication, and a proactive approach are essential. Youth- and family-centered education improves healthcare knowledge, self-management, self-advocacy, and appropriate interdependence and helps young adults to take ownership of their health.

*Summary* Nurses play an integral role within the multidisciplinary team in supporting seamless, successful transition and transfer of CHD patients from pediatric to adult care thereby reducing loss to follow-up and lapses in care. Most experiences and recommendations are based on retrospective studies and expert consensus. It is imperative to evaluate the impact of structured and planned transition/transfer programs on the outcomes. Hence, prospective, randomized trials are required to document if implementation of structured intervention transition programs improve knowledge, patient experiences, and outcomes of congenital heart defect survivors.

**Keywords** Congenital heart disease · Heart defects · Congenital · Transition · Adolescence · Patient-centered care

## Introduction

Due to great advances in medicine and clinical care, the majority of patients with congenital and childhood onset cardiovascular conditions are now surviving to adulthood [1]. This has created a large and rapidly growing population of adults requiring specialized cardiac care [2•]. The number of adult congenital heart disease (ACHD) survivors now exceeds the number of current pediatric patients, with an impressive increase of >50% in congenital heart disease prevalence in adults since 2010 [3•]. Although CHD patients are living longer, many will face residual medical complications and psychosocial issues after their initial treatment(s) as children [4, 5•]. These initial medical/surgical treatments are thought to be

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repairs, not cures [4]. The improved survival of CHD patients has led to increased emphasis placed on a coordinated and seamless transition of patients from pediatric focused to adult-centered cardiac care [2•]. High proportions of young adults are lost to follow-up or experience long gaps in care after leaving pediatric cardiology, although lack of cardiology follow-up begins often during childhood, even among those with severe lesions [6]. One or more missed-cardiology appointments and lack of awareness of the need for follow-up predict care laps for 3 years or more [7].

Canadian and German studies have reported that one half to three quarters of young adults with CHD are not appropriately followed within the recommended ACHD system [8–10]. A 2015 Canadian survey by Moceri and colleagues indicated that less than half of ACHD patients are receiving appropriate follow-up care according to recommended guidelines [11]. Furthermore, these individuals are at risk of substantial morbidity and mortality in their early to mid-adult years and place a significant burden on healthcare resources [12].

Up to 60% of patients with lapses in care received a diagnosis of hemodynamic significance upon representation to ACHD care [13]. In addition, patients with such lapses in care had a 3.1 greater likelihood of requiring urgent interventions [14].

The aim of this article is to (1) define the concepts of transition and transfer, (2) discuss the historical background of transition, (3) list common barriers to transition, (4) describe the current pediatric and adult experiences at three major CACHNET (Canadian Adult Congenital Heart Network; www.cachnet.ca) centers in Ontario in respect to the current CHD transition guidelines, and lastly (5) share practical strategies and assist in the development or evolution of current transition programs.

## Transfer and Transition Concepts

Transition is a process that occurs over years and requires collaboration among all stakeholders including patients, families, pediatric, and adult care practitioners [15•]. A formal transition program not only prepares adolescents and their families for transfer of care, but it also facilitates continuous care that is both age and developmentally appropriate [16••].

In order to ensure an optimal transition process, a multidisciplinary team approach is paramount. Transition is conceptualized as a process, a shift in responsibility of the healthcare management from the parent(s) to the adolescent patient [2•, 17].

The American Heart Association (AHA) recommends best practices to guide the transition of patients with CHD and has defined three stages of transition process: pre-transition, transition, and transfer of care [16••].

*Pre-transition* begins early, when the idea of lifelong medical follow-up is introduced and emphasized by the pediatric provider to both the patient and family [18].

*Transition* occurs when the adolescent patient is deemed developmentally ready to participate in his or her own healthcare decisions. There is a key emphasis on education throughout this transition stage [2•, 18]. Transition also occurs for patients with developmental/cognitive impairment who are not expected to lead components of their own healthcare as an adult. For this population, transition preparation is performed with the patient's parents or caregivers to establish a partnership and formulate a long-term care plan [15•]. The transition process must be individualized to the individual patient and be appropriate to the mental and psychological development. Even if the patients do not change healthcare providers, they benefit from a transition process [17].

*Transfer* is an event, when the patient is discharged from pediatric care and referred to adult care [2•, 18]. Timing of the transfer ideally should be flexible and developmentally appropriate; however, in some countries like Canada, a mandatory age of transfer exists at 18 years [15•].

## Transition Guidelines

Current international guidelines suggest three types of ACHD care: (1) specialist care, (2) shared care, and (3) non-specialist care [4]. Specialist care is provided by an ACHD cardiologist who is a specialist in a tertiary care center, while shared care describes a collaboration between an adult cardiologist and a specialty ACHD cardiologist. Non-specialist care is provided by a general cardiologist or primary care provider without training in ACHD, but with access to specialized care when needed [4]. The Canadian Association of Paediatric Health Centers recently published national transition guidelines that emphasized the importance of institutional and national collaboration and provided a framework for a supportive process to transition from pediatric to adult healthcare systems [19].

Guidelines exist to guide the frequency of follow-up visits according to the severity of lesion. Patients with complex heart defects, such as cyanotic heart disease or transposition of the great arteries, should be seen every 6–12 months [4]. Patients with lesions of moderate complexity, e.g., tetralogy of Fallot or coarctation of the aorta, should be seen every 1–2 years either at a specialty center or in shared care as appropriate. Most adults with CHD of moderate or great complexity are at significant risk for complications such as heart failure, arrhythmia, additional interventional, or surgical procedures and premature mortality [5•]. Adolescents with CHD lesions of mild complexity (e.g., isolated atrial or ventricular septal defects, patent ductus arteriosus without complications) should be seen at least once by a specialized ACHD cardiologist after their transfer to adult care, and then follow up every

3–5 years either as a shared care or as a non-specialized care [4].

## Transition Process

The process of transition for CHD patients should begin in early adolescence, around 12 years of age to allow the development of the necessary self-care skills [16••]. "Envisioning a future" has been identified as an important first step in the transition process and can be assisted with creation of a written healthcare transition plan [20].

The AHA scientific statement recommends a formal transition program that includes a transition coordinator, typically a clinical nurse specialist who has knowledge of the developmental stages in pediatrics and adolescence [16••]. The transition coordinator acts as a liaison between the pediatric and adult care providers and promotes continuity of care [16••]. Nurse led transition interventions with focus on education have demonstrated improved healthcare knowledge [12] and self-management skills, self-advocacy, and appropriate interdependence [2•].

## Barriers to Transfer and Transition

Many potential and actual barriers exist that can impede successful transition and finally transfer. It is essential to consider these barriers listed in Table 1, prior to developing a transition/transfer process within one's congenital heart disease program.

**Table 1** Potential and actual barriers to successful transition and transfer

| Barrier to transfer/ transition | Authors | Additional comments |
|---|---|---|
| - Patient and/or family attachment to pediatric clinician<br>- Perceived lack of qualified adult providers in ACHD specialty<br>- Patient emotional/cognitive delay<br>- Parent/patient emotional attachment to institution<br>- Patient non-compliance with transfer<br>- Unstable social situation<br>- Patient unstable medical condition<br>- Insurance issues | Fernandes et al. (2012) [21] | |
| - Patient adherence<br>- Patient relocation<br>- Attachment to specialty clinic<br>- Transition/transfer not seen as essential elements in care of CHD patients<br>- Lack of structured transition programs | Lecomte et al. (2016) [22] | |
| - Delay completion of developmental tasks or stages due to repeated hospitalizations/illness impacting self-image or self-esteem<br>- Lack of health care/life insurance**<br>- Lack of primary care provider "medical home" | Sable et al. (2011) [16••] | **There is a significant change in healthcare coverage at the very time of transfer to adult care in the USA.<br>American Academy of Pediatrics medical home policy statement |
| - Parental over protection<br>- Patient may feel suddenly overwhelmed when faced with making difficult decisions and participate in conversations around complications/shorten life span | Saidi and Kovacs (2009) [17] | |
| - Parental anxiety about transfer<br>- Parental anxiety around giving up responsibility<br>- Parental involvement in their child's care—affecting the level of care<br>- Parents and youth have very specific negative impressions of care in the adult system | Reiss et al. (2005) [20] | |

## SickKids Hospital: History and Good 2 Go Transition Program

Approximately 257,000 Canadians have CHD, and two thirds of them are adults [3•]. It is estimated that 50% of this population will be faced with possible complications, repeated interventions, and or premature/sudden death [23].

In Ontario, once a patient is 18 years old, they can no longer be admitted to a pediatric hospital which provides patient care in an environment appropriate for their age. It is therefore crucial that patients and families receive the necessary transition preparation, ensuring safe and timely transfer with continuity of care. Over the past 10 years, approximately 200–250 new referrals per year were sent from the Labatt Family Heart Centre (LFHC) at SickKids Hospital to Toronto Congenital Cardiac Centre for Adults (TCCCA) [24]. It was recognized that a formalized approach to managing the transfers and ongoing care would be required.

SickKids launched a hospital wide initiative, the *Good 2 Go Transition Program* in 2006 to address the increasing

**Table 1** (continued)

| Barrier to transfer/ transition | Authors | Additional comments |
|---|---|---|
| - Limited knowledge about own congenital cardiac lesion<br>- Belief that they are cured<br>- Misperceptions about their prognosis and long term consequences of their actions, failed to recognize the importance of uninterrupted cardiology care<br>- Have not developed self-care strategies<br>- Unable to make independent decision about their health | Mackie et al. (2014) [12] | Patients who have had cardiac-related procedures within the past 5 years (before transfer) are less likely to be lost to follow-up than those whose last procedure was greater than 5 years |
| - Youth with special healthcare needs (developmental/-cognitive impairment) have additional psychosocial difficulties | CAPHC Guideline for Transition From Pediatric to Adult Health Care for Youth with Special Health Care Needs June (2016) [9] | - Impaired social functioning<br>- Anxiety disorders<br>- Mood disorders/depression<br>- Suicidal ideation/attempts<br>- Engaging in risky behaviors |
| - Simple CHD lesion<br>- Not having had previous cardiac surgery<br>- Differences in stakeholder perspectives: gaps in communication and coordination of care, discrepancies in expectations and roles, and unanticipated challenges | Goossens et al. (2011) [4] | |
| - Stable CHD: asymptomatic, feeling well<br>- Stable CHD: not on long-term medications—less exposed to health system<br>- Absence of structured transition programs | Moceri et al. (2015) [11] | |
| - Patients unconcerned with transition/transfer "no big deal"<br>- Lacked knowledge about congenital cardiac lesion | Amaria et al. (2011) [25] | Adult system is viewed as unsupportive and less nurturing<br>Adult providers are viewed as busier and have less time to answer questions<br>Treatment and services are seen as fragmented/lacking multidisciplinary approach |
| - Discharge from pediatric hospital with no identified ACHD follow-up<br>- Patient recalled being told that follow-up was not required | Yeung et al. (2008) [13] | Adult system seen as neither collaborative nor communicating with the pediatric system |
| - Incomplete acquisition of executive function (limited insight into the impact of poor adherence, lack of impulse control)<br>- Immaturity of the prefrontal cortex: difficulties with self-advocacy and self-management | Casey (2000) [26] | |
| - Lack knowledge about their condition<br>- Lack knowledge about implications of transition on their cardiac care<br>- Lack knowledge about what to expect at their first adult cardiology outpatient clinic visit | Moons et al. (2009) [27] | |

needs of chronic illness patients and families preparing for transfer to an adult center. The Good 2 Go Program's goal is to equip transitioning youth with the necessary skills and knowledge to advocate for themselves, maintain healthy lifestyle behaviors, and navigate the adult system successfully [25]. In addition, they later developed a Complex Transition Care Program to meet the special needs of youth who face complex transitions, creating further resources to prevent crisis during the transition process.

In 2008, the Good 2 Go Program partnered with the newly established *Toronto CHD Transition Task Force*. This interdisciplinary working group is composed of care providers from both the LFHC and TCCCA programs. The Task Force collaborated on several transfer and transition initiatives including education, focus on transfer preparation, and coordination of care [15•].

In preparation for transition, patients 14 years and older are seen on their own for part of their clinic visit to encourage development of self-management skills. Favorable outcomes have been demonstrated by nurse led transfer clinics where nurses educate patients about the importance of attending follow-up appointments and helped to facilitate the introduction to the new adult provider [28]. All patients in this study who completed the post-transfer survey felt that they had a good understanding of their health condition at the time of transfer, and meeting their new adult provider was rated as one of the most useful elements of the clinic.

Other transition initiatives developed over the years by the Task Force have included a cardiac condition specific MyHealth Passport, transition education evenings, patient and family education events, iHeartChange website, and three-sentence summary. The *MyHealth Passport* is a portable, convenient documentation of the patients' health information. This wallet-sized card lists medical conditions, allergies, medications, past procedures, treatments, and other relevant health information. Patients are encouraged to carry the card at all times and present it to healthcare providers when needed [29]. The *three-sentence summary* is a brief outline of the (1) patient's age, diagnosis, brief medical history, (2) treatment plan, and (3) questions/concerns to discuss during visit to clinic [25]. This summary is introduced and practiced with the clinic nurses at SickKids Hospital.

*Transition Evenings* began in 2002 to further prepare patients and families for transfer to the adult program. The evening includes an opportunity to meet the adult care team, a tour of the adult clinic, and meet a graduate patient to learn about their experience in the adult healthcare system. Each attendee receives a transition package that includes various information about the adult program, including a brochure from the Canadian Congenital Heart Alliance (CCHA; www.cchaforlife.org), a non-profit CHD patient advocacy group.

Due to the distance, many patients live from the hospital; it is not always feasible for them to attend the Transition Evenings. Therefore, the LFHC promotes a CHD specific website called *iHeart Change*: Internet intervention to Help Emerging Adults Ready for Transition Change (iHeartChange). Under the great leadership of Dr. Adrienne Kovacs, iHeartChange was developed by members of the Task Force targeting the transition and transfer of CHD adolescents who utilize electronic media. A major strength of the iHeartChange website is its broad scope of focus (www.iheartchange.org). It includes six content "buckets": (1) medical information, (2) lifestyle information, (3) coping with CHD, (4) connecting with other patients, (5) becoming more independent, and (6) an introduction to the adult care team. The website has demonstrated strong feasibility in the youth with CHD who chose to access the site as part of a research study. Feedback in terms of design and content was extremely positive. Teens found the website easy to navigate and thought that the content was useful, easy to understand, and trustworthy [24, 30].

In 2011, the Good 2 Go Transition Program began developing a Complex Transition Care Program to meet the needs of youth who face complex transitions. This consisted of creating resources, providing consultation and education to care providers, building partnerships with adult service organizations, and offering direct clinical support to patients and their families in order to prevent crisis during the transition process (Fig. 1).

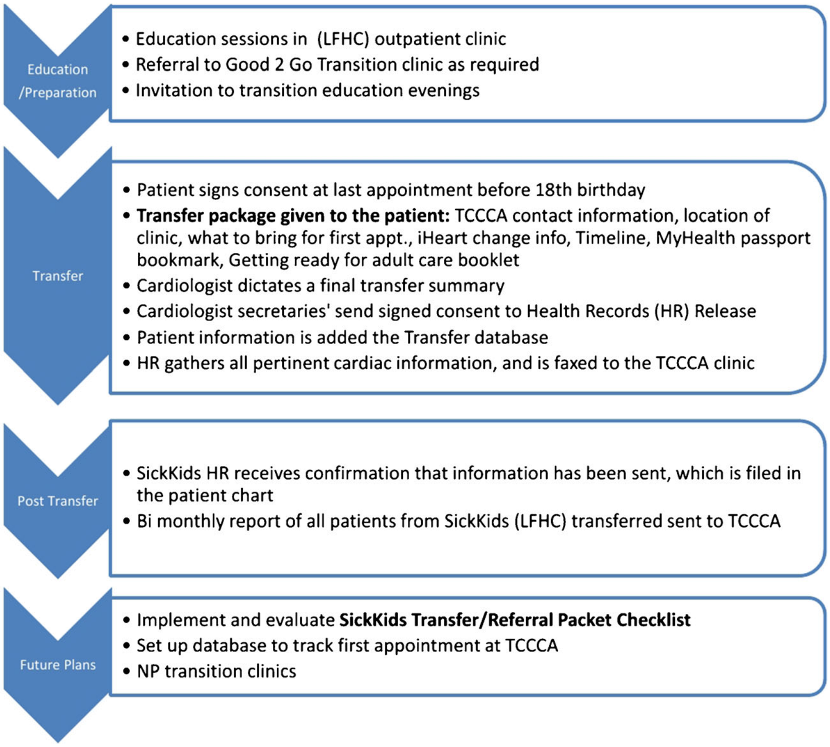
**Fig. 1** Goals of the transition care and transfer program. *LHFC* Labatt Family Heart Centre, *TCCCA* Toronto Congenital Cardiac Centre for Adults

Education /Preparation

- Education sessions in (LFHC) outpatient clinic
- Referral to Good 2 Go Transition clinic as required
- Invitation to transition education evenings

Transfer

- Patient signs consent at last appointment before 18th birthday
- **Transfer package given to the patient:** TCCCA contact information, location of clinic, what to bring for first appt., iHeart change info, Timeline, MyHealth passport bookmark, Getting ready for adult care booklet
- Cardiologist dictates a final transfer summary
- Cardiologist secretaries' send signed consent to Health Records (HR) Release
- Patient information is added the Transfer database
- HR gathers all pertinent cardiac information, and is faxed to the TCCCA clinic

Post Transfer

- SickKids HR receives confirmation that information has been sent, which is filed in the patient chart
- Bi monthly report of all patients from SickKids (LFHC) transferred sent to TCCCA

Future Plans

- Implement and evaluate **SickKids Transfer/Referral Packet Checklist**
- Set up database to track first appointment at TCCCA
- NP transition clinics

## History of the TCCCA Program

The first ACHD clinic was opened in 1959 and the ACHD program was officially formalized at Toronto General Hospital (TGH) in 1982. Since 1989, the ACHD program adopted the name TCCCA. More than 18,500 adults with CHD were referred and treated at TCCCA; 50% of these patients are still actively followed. The number of actively followed patients has doubled within the last 10 years, which reflects the success story of congenital heart disease owing to great advances in medicine and congenital heart disease surgery and interventions. The sources of new referrals are transfers from SickKids and referrals from the community (patients lost to follow-up or with newly diagnosed congenital heart defects). Understandably, there is an increasing disconnect between patient demand and resources available and emphasizes the urgent need of resource reallocation.

It is not only the number, but it is also the complexity of patients which is increasing. Introduction of complex interventional surgical procedures allows children born with a CHD of moderate and great complexity to survive until adulthood. The patient's medical history begins at birth (or even before birth) and many of them underwent several interventions during the first 18 years of their life and/or already faced complications from their congenital heart defect (e.g., arrhythmias, heart failure, pulmonary hypertension, psychosocial issues), which impact outcome during adult life. Hence, medical history during pediatric care cannot be ignored. It is paramount and critical to have an excellent, comprehensive summary provided by the pediatric cardiologist who transfers the patient to adult care. The Transition Task Force consisting of members from SickKids and the TCCCA prepared a Transfer/Referral Packet Checklist in order to assist the referring providers in preparing a comprehensive transfer letter (Table 2). This letter will then allow provision of developmentally appropriate, high quality cardiac care to adults graduating from pediatric care.

## University of Ottawa Heart Institute

The Adult Congenital Heart Disease (ACHD) Clinic at the University of Ottawa Heart Institute (UOHI) began in 2002 as a result of the recognized needs of this growing population. Seven hundred and fifty patients were seen by two cardiologists, an interventional pediatric/adult cardiologist, a pediatric cardiac surgeon, and a registered nurse. In 2006, the Ministry of Health of Ontario denoted the ACHD clinic as a regional congenital heart disease center capable of meeting the needs of the subspecialty population. The program now has specialized diagnostic imaging (including MRI) and provides electrophysiology and high risk maternal-fetal services to their ACHD patients. There are currently 3500 patients registered to the UOHI ACHD clinic with 2000 actively followed.

At 18 years of age, patients are transferred from the Children's Hospital of Eastern Ontario (CHEO) to adult care. A comprehensive review of the patient's cardiac history is performed and a close out letter completed prior to transfer. This letter includes the health history, current cardiac status, and follow-up plan with clinic visit frequency. Patients are asked to explain their heart condition in their own words. The patient's contact information is verified and must include patient's own telephone number and e-mail address. Risk behaviors are noted (smoking, alcohol use, use of recreational/street drugs). The letter also highlights family composition, the names of parents/guardians, and significant persons in the patient's life. Patients who require additional needs or may require complex coordination of care are flagged. In addition to the close out letter, the CHEO will notify the ACHD clinic at UOHI by phone or e-mail of the pending transfer of a complex patient. Patients are informed that the ACHD clinic will contact them with their first appointment details within 2 months of the closeout visit. Lastly, the ACHD clinic contact number is provided to the patient if they have not received their first appointment notice.

The ACHD nurse practitioner reviews the transferred chart along with the close out letter for completeness and triages for urgency, required testing, and the timing of the first appointment. Every effort is made to acquire pertinent documents such as specialist consult and OR reports, previous heart catheterization, or diagnostic testing information that may not be included in the transfer chart.

At the initial visit, the patient is offered the opportunity to meet with the nurse practitioner to review information or questions that young adult may have. Anatomy and physiology teaching is performed by the nurse practitioner using diagrams from Mullens' cardiac atlas and internet based resource [31]. Whether the first visit is with the nurse practitioner or in combination with the ACHD cardiologist, a comprehensive review will include full cardiac history, family history/composition, non-cardiac comorbidities, medications, bacterial endocarditis and antibiotic prophylaxis, psychosocial situation, life goals, physical activity, risk behavior(s), contraception, and pregnancy risk.

When necessary, appropriate specialist referrals are initiated at the first visit including anticoagulation, pacemaker/device, contraception, special pregnancy, vocational counseling, and cardiac rehabilitation, dietary, and psychological services.

**Table 2** The Toronto Transfer Checklist for CHD patients

## SICKKIDS TRANSFER/REFERRAL PACKET CHECKLIST

**Referrals to the Toronto Congenital Cardiac Centre for Adults (TCCCA)**
**Peter Munk Cardiac Centre, Toronto General Hospital, UHN; Fax: 416-340-5014**

**Patient Name:** ______________________ **Date of Birth:** ____/____/______ **SickKids MRN:** ____________
**Date of Transfer:** ___/___/______ **Referring Cardiologist:** ___________________ **OHIP #:** ______________
**Cell #:** __________________ **E-mail:** ______________________ **Preferred language:** ________________
**Address:** ____________________________________________________________________

***To referring providers:*** *Our aim is to provide developmentally-appropriate, high quality cardiac care to patients transferred to our program.* ***This checklist must accompany all transfer/referral packets.***

**Comprehensive summary (transfer letter) including the following:**

- ☐ Original cardiac diagnoses and Current cardiac status
- ☐ Surgical/Interventional history (including names and years of procedures)
- ☐ Other medical comorbidities
- ☐ Current medications and dosages
- ☐ From last clinic visit: height, weight, BP, O2 saturation

**Reports (tick if included):**

- ☐ Clinical conference summaries
- ☐ Surgical reports
- ☐ Diagnostic heart catheterization reports
- ☐ EP / PM / ICD reports
- ☐ Genetic testing reports
- ☐ Cognitive testing (if performed)

**Additional Information (if yes, additional details must be provided in transfer letter)**

- ☐ Yes ☐ No Hx of heart failure
- ☐ Yes ☐ No Hx of arrhythmia, PM or ICD
- ☐ Yes ☐ No Genetic syndrome
- ☐ Yes ☐ No Clinically significant allergies
- ☐ Yes ☐ No Activity restrictions
- ☐ Yes ☐ No Endocarditis prophylaxis is required
- ☐ Yes ☐ No Anesthesia required for routine non-invasive testing (eg, ECG, CT)
- ☐ Yes ☐ No Cognitive disability or special educational needs
- ☐ Yes ☐ No Significant psychological, social, or family challenges
- ☐ Yes ☐ No Any concerns re. patient/family readiness for transfer of care

**Other referrals (note: separate referral letters are required)**

- ☐ EP / PM / ICD clinic
- ☐ Other ______________________________
- ☐ Dalglish Hearts & Minds Clinic (dedicated clinic for 22q11.2 microdeletion syndrome)

**Continuity of Care:**

- Date of last SickKids outpatient appointment: ___________________________
- Recommended date of first ACHD visit (how many months/years): ____________
- Is referral urgent (ie, patient should be seen within 6 months)? ☐ Yes ☐ No
- Any special tests recommended at first clinic visit (note: ECG, CXR, TTE, CP study are standard): __________

____________________________________________________________________

- Contraception/inheritance risk has been discussed with patient: ☐ Yes ☐ No
- Patient is capable of making his/her own health care decisions: ☐ Yes ☐ No
- Patient is aware of interventions anticipated within next 3 yrs: ☐ Yes ☐ No ☐ N/A
- Patient understanding of CHD & future health expectations: ☐ Good ☐ Fair ☐ Poor

Due to the volume of information provided during this initial visit, it may be necessary for more than one session. The whole transfer process has been summarized in Table 3.

Table 3 University of Ottawa Heart Institute: pre- and post-transfer

| | |
|---|---|
| Pre-transfer up to age 18 years Children's Hospital of Eastern Ontario (CHEO) | At closeout or preferably a few visits prior to closeout:<br>1) Review of anatomy and physiology and surgeries/interventions<br>2) Transition tool completion highlighting potential problems<br>a) Knowledge deficits regarding heart condition<br>b) Smoking<br>c) Alcohol consumption<br>d) Recreational drugs<br>e) Anxiety and depression<br>3) Review of information related to:<br>a) Risk of infective endocarditis, rationale for antibiotic prophylaxis when required, importance of meticulous dental hygiene<br>b) For females: appropriate contraceptive methods<br>c) Heart healthy nutrition<br>d) Benefits of active lifestyle, exercise restriction<br>e) Medications |
| Transfer at 18 years of age patient transfer to adult care<br>University of Ottawa Heart Institute (UOHI) | 1) Closeout letter followed by chart transfer:<br>a) Closeout letter by cardiologist containing details of anatomy, all cardiac surgery and interventional procedures, list of medications, allergies, test results, physical assessment, plan for reassessment<br>b) Most recent test reports and imaging<br>c) Family composition<br>d) Signed consent by patient or caregiver allowing transfer of medical record and communication with family members (parents/other)<br>e) Contact information for patient and family including phone numbers and e-mail<br>2) For the complex or at risk patient, telephone contact from the pediatric team (nurse or physician) to the ACHD team<br>3) Notification by e-mail from the pediatric administrative assistant of the impending transfer<br>4) Business card provided to patient and family with expectation that contact from ACHD team will occur within 1 month<br>5) Uploading of pertinent pediatric reports to patient's electronic medical file (operative notes for cardiac surgery, interventional, and diagnostic heart catheterization reports) |
| Post-transfer | 1) Verification of chart content for completeness (letters, test reports, imaging, operative reports, genetics, and other specialist reports)<br>2) Triaging for timing of first assessment<br>3) Upon reception of chart, phone contact with patient/family by advanced practice nurse within 1 week<br>4) Review of plan for assessment along with timing of appointments<br>5) Confirmation of contact information and reiteration of ACHD contact number<br>6) Offer to patient for one-on-one appointment to review transition and answer questions<br>7) Appointments provided to patient by ACHD clerk<br>8) Information package sent to patient including introduction letter, pamphlet on Canadian Congenital Heart Alliance (CCHA)<br>9) Referral to other specialties when appropriate:<br>a) Device clinic<br>b) Anticoagulation clinic<br>c) Women's Health clinic (e.g., contraception)<br>d) Prevention and rehabilitation (vocation, exercise prescription, nutrition, psychologist, social work)<br>10) Make patient aware that access to their electronic medical file is available to them |
| Future direction | 1) Biannual multidisciplinary transition sessions for patients and families<br>2) Mentoring program between CCHA and transition patients<br>3) Questionnaire for patient at pediatric closeout to determine areas that patient wishes to focus on upon transfer to ACHD<br>4) Update transition tool to reflect advances in electronic medical record<br>5) Testing for depression and anxiety at transition with referral to psychological services when appropriate |

## Practical Strategies

Extensive evidence, including the American Heart Association scientific statement, has described different

**Table 4** Practical strategies

| Recommended strategy | Center where strategy currently applied | References | Benefits |
|---|---|---|---|
| Medical home (primary care provider) | All | Sable et al. (2011) [16••]<br>Lecomte et al. (2016) | 1. Ensures quality and continuity of care<br>2. Screening for non-cardiac health issues and acquired heart conditions<br>3. Psychosocial health<br>4. Avoid multiple specialists functioning independently |
| Outpatient nursing transition clinic for transferring ACHD patients | UOHI | | 1. Comprehensive educational curriculum<br>2. Assessment for risk behaviors<br>3. One on one sessions that are based on individual learning needs<br>4. Review of anatomy<br>5. Triages urgency of first cardiology visit |
| Transition Task Force/working group | SickKids/TCCCA | Kovacs et al. (2012) [24] | 1. Multidisciplinary approach to transition<br>2. Planning and implementation of new transition program<br>3. Improve on existing transition program |
| Pediatric nurse led transition clinic—Good 2 Go | SickKids | Mackie et al. (2014) [12]<br>Kovacs et al. (2012) [15•] | 1. One-on-one attention<br>2. Self-management skills development<br>3. Knowledge acquisition of patient's specific congenital heart disease<br>4. Prepare youth with the necessary advocacy skills<br>5. Maintain health promoting behaviors |
| Transition evening | SickKids/TCCCA | Kovacs et al. (2012) [15•] | 1. Pre-transfer tours of adult clinic<br>2. Meet the adult team of providers |
| Comprehensive transition plan/transfer letter | SickKids/UOHI | Saidi and Kovacs (2009) [17] | 1) Emphasizes starting early, prior to transfer<br>2) Prepares patients and families in advance<br>3) Encourages participation from patient and family<br>4) Prompts patients and family to consider future expectations<br>5) Documents the need for lifelong specialized cardiology follow-up |
| Complex Transition Care Program—CHD patients with cognitive impairment | SickKids | CAPHC June (2016) [19] | 1. Developmentally appropriate<br>2. Patient centered/family centered care<br>3. Adaptable to the abilities and complexities of the youth |
| Health education initiatives for patients and families | SickKids/TCCCA | Amaria et al. (2011) [25]<br>Kovacs et al. (2012) [15•]<br>Sable et al. (2011) [16••] | 1. Three-sentence summary<br>2. Readiness checklists<br>3. Myhealth passport<br>4. iHeartChange |
| Educating adult providers/practitioners regarding the unique attributes of adolescent/young adults | | Amaria et al. 2011 | |
| Promoting collaboration and communication between pediatric and adult congenital heart disease programs | | Amaria et al. (2011) [25] | |
| Shared database of health records for pediatric and adult CHD providers | | Amaria et al. (2011) [25]<br>Kovacs et al. (2012) [15•] | |
| Young adult clinics jointly staffed by both pediatric and adult care providers | | Amaria et al. (2011) [25] | |
| Establishing clear document transfer policies | All | Amaria et al. (2011) [25] | 1. Transfer of complete chart/medical documentation<br>2. Timely appropriate appointments |
| Establishing a transition coordinator role | TCCCA | Sable et al. (2011) [16••] | 1. Initial contact person/liaison between pediatric and adult setting<br>2. Ongoing, coordinated communication/collaboration between settings |

clinical approaches or strategies to optimize the transition process for CHD patients. These practical strategies listed below in Table 4 have been summarized in order to assist in the development of a formal transition process or improve on an existing transition program.

## Conclusion

The number of patients living with congenital heart disease continues to grow as more and more children are surviving into adulthood, including those with complex lesions. This steady growth in patients has created a "tsunami" within the congenital heart disease world, as healthcare providers are challenged to meet this rapidly increasing demand on the healthcare system. Although healthcare practitioners strive for patient/family centered care, they must consider healthcare costs by developing innovative ways to provide high-quality care based on collaboration and partnerships. These relationships are key to the success of the transition process within congenital heart disease.

Many patient-specific and local, institutional-specific barriers exist during the transition process, leading to "lost to follow-up" or lapses in care for CHD patients. Healthcare providers are constantly faced with these challenges; however, if CHD programs can collaborate on their clinical experiences and practical strategies, all programs can benefit. A close collaboration and interaction between the local pediatric program and the ACHD program are paramount to establish a concept for successful transition and transfer, to improve continuity of care for a chronic disease, and to reduce the number of patients lost to follow-up. A comprehensive approach considers the various transition guidelines and the needs of the individual and their family. Furthermore, nursing champions supported by a multidisciplinary team is recommended to ensure a proper handoff in the transition process of patients with congenital heart disease.

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**Compliance with Ethical Standards**

**Conflict of Interest** Angela Lee, Barbara Bailey, Geraldine Cullen-Dean, Sandra Aiello, Joanne Morin, and Erwin Oechslin declare that they have no conflict of interest.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

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