



The Toronto congenital heart disease transition task force

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ABSTRACT

There is consensus regarding the importance of a thoughtful and coordinated transition process to support adolescents and young adults with congenital heart disease (CHD) as they take increasing responsibility for their health care management and transfer from pediatric to adult care. Few CHD teams, however, offer formal transition programs. This paper describes the development of the Toronto CHD Transition Task Force, which is an interdisciplinary group of pediatric and adult providers committed to undertaking practical strategies to optimize the transition and transfer of adolescents and young adults with CHD. Task Force initiatives are described in three categories: (1) patient and family education, (2) preparation for transfer, and (3) coordinated transfer of care. It is hoped that the experiences and resources of this Task Force will assist other programs interested in developing or expanding their transition services.

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1. Introduction

There is agreement regarding the value of a thoughtful and coordinated transition for adolescents and young adults with congenital heart disease (CHD) and the components of a comprehensive transition program have been described [1,2]. In reality, however, the majority of cardiology programs do not have formal transition programs. Hilderson et al. surveyed 228 American and European CHD programs about their transfer and transition practices, of which 69 responded [3]. Fifty-one (74%) of responding centers transfer patients to adult care at a median age of 18 years; of these 51, only 15 (29%) reported having a structured preparation for patients and family. Thus, within CHD, there are few models of a comprehensive transition program. In this paper, we describe the development and initiatives undertaken by the interdisciplinary Toronto CHD Transition Task Force. We begin with a brief review of transfer and transition within the CHD context.

1.1. Transfer and transition in congenital heart disease

Experts recommend a formal transition process to assist adolescents and young adults with CHD with becoming more responsible for their health care [4–7]. The goal is the maximization of “lifelong functioning and potential through the provision of high-quality,

developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood [8].” The reality for many patients, however, is an abrupt transfer to adult care, retention in the pediatric setting longer than appropriate, or a disconnect from health care altogether [9,10].

Transfer and transition are related though not synonymous terms. Transfer is an event, namely the discharge of patients from pediatric care and referral to adult care. Unfortunately, Canadian and German studies suggest that one-half to three-quarters of young adults with CHD are not appropriately followed within the adult congenital heart disease (ACHD) system [10–12]. Mackie et al. also demonstrated that approximately half of young adults living with CHD in Quebec, Canada had not received cardiac follow-up after their 13th birthday [13]. Therefore, discussions about the importance of life-long cardiac surveillance cannot wait until late adolescence. Of most concern is the potential negative impact of absence from specialized cardiac care. In a study of 158 adults with CHD of moderate or great complexity, 63% had lapses in care of at least 2 years; one-third recalled being told that cardiac follow-up care was not required [14]. Patients with lapses were more likely to require urgent cardiac intervention upon eventual presentation for medical care [14].

Transition is a process that occurs over years and requires collaboration among patients, families, and pediatric and adult health care practitioners. Based on theories of anticipatory guidance, an early start to discussions surrounding transition is extremely important [4,7,15]. Preparation entails the acquisition of self-management skills and young people will not miraculously develop such skills upon their 18th birthday. As children and adolescents mature, they will variably develop the knowledge, attitudes and life skills that support engagement with chronic

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illness management practices [16]. As age- and developmentally appropriate, the process of transition should be initiated by early adolescence, around 12 years of age [4,17]. The responsibility for health care management ideally shifts from parents and family to patients in order to provide “uninterrupted health care that is patient-centered, age and developmentally appropriate, flexible, and comprehensive [2].” Qualitative research suggests that adolescents with CHD recognize the shift in roles between patients and parents [18]. Although adolescence is typically the focus of transitional care, the post-transfer period should not be ignored. Ongoing patient and parent education is an important element of a successful transition [1,2,4,19]. A comprehensive education curriculum includes matters related to a patient’s CHD diagnosis and treatment as well as wider lifestyle implications (e.g., family and career planning).

2. Development of the Toronto CHD transition task force

In Ontario, Canada, there exists a mandatory age of transfer such that patients cannot be admitted to pediatric hospitals once they turn 18. In Toronto, patients can literally cross the street from the Labatt Family Heart Centre (LFHC) at The Hospital for Sick Children (SickKids) to the Toronto Congenital Cardiac Centre for Adults (TCCCA) at the Peter Munk Cardiac Centre, University Health Network (UHN). Despite this geographic advantage, a study conducted at our own institutions demonstrated that 53% of Canadian teenagers with complex CHD had not been seen at one of the 15 Canadian Adult Congenital Heart Network (CACHNET) centers within 2 years of pediatric discharge [10]. We are currently reviewing contemporary Toronto data, and anticipate that the rate of successful transfer has significantly improved since this study (that included a historical population of patients born between 1978 and 1980) was reported. It is unknown whether we have reached a level of success documented in a recent Belgian study, in which over 90% of patients were in follow-up care [20]. Over the past 10 years, the TCCCA has received 200–230 new referrals annually from the LFHC. The value of a formalized approach to optimizing the transfer and, most importantly, the ongoing care of these patients was thus recognized.

In Toronto, the initiative to improve CHD transition began over 10 years ago as a working group of pediatric and adult CHD nurses who met regularly with the support of their medical directors. This working group initiated Transition Evenings and TCCCA welcome letters, which will be described further. The collaboration and commitment to transition among LFHC and TCCCA providers was formalized in September 2008 under the leadership of the TCCCA Director. Task Force meetings were initially held every 2 to 3 months, but with initiatives now underway, focused meetings are held every 6 months.

The Task Force is comprised of providers from the LFHC, the TCCCA, and the SickKids Good 2 Go Transition program. It is an interdisciplinary group comprised of staff physicians, cardiology fellows, nurses/nurse practitioners, and psychologists from the pediatric and adult programs. The designation of a specific transition coordinator has been recommended [8,21,22]. Within the CHD Transition Task Force, however, a transition coordinator with protected time for this role does not currently exist, primarily due to the absence of targeted funding. Instead, communication regarding transfer/transition issues occurs at Task Force meetings or between individuals most responsible for particular issues. The Task Force recognizes that many of the transition initiatives occur in the pediatric setting and are led by LFHC clinic nurses. The Task Force is very appreciative of this group of nursing colleagues who are genuinely supportive of transition efforts.

The Task Force has benefited from close collaboration with the SickKids Good 2 Go Transition program (www.sickkids.ca/good2go) [23]. This hospital-wide initiative was established in 2006 to address the increasing needs of patients and their families preparing to leave the pediatric hospital and move to adult care. The goal is to prepare the youth with chronic health conditions to leave SickKids at 18

with the necessary skills and knowledge to advocate for themselves (or through others), maintain health-promoting behaviors, and utilize adult health care services appropriately and successfully. It serves as a resource within the hospital and liaises with individual medical programs to begin preparing patients and families early, so that by the time each patient reaches young adulthood, engagement with health care and self-management skills have become second nature and embedded in their daily lives. Good 2 Go has a three-pronged approach: (1) education and staff support, (2) resource identification and development, and (3) support and evaluation strategies.

Task Force members have collaborated on several initiatives focused on transfer and/or transition (see Table 1). The documents described in this paper can be obtained by contacting one of the authors or through the Transition Tools and Resources link of the Good 2 Go Transition website (<http://www.sickkids.ca/Good2Go/What-we-do/index.html>).

3. Educational initiatives

3.1. MyHealth Passport

Patients with CHD are recommended to carry portable, convenient documentation of their health information [2]. For this reason, the Task Force supports the practice by which patients create a MyHealth Passport, either in the pediatric or adult clinic [24]. The MyHealth Passport is a wallet-sized card that lists medical conditions, past procedures/treatments, medications, allergies, and additional health information. Patients are encouraged to carry the Passport at all times and present it to providers as needed. The cardiac template was developed in collaboration with the Good 2 Go program and an inter-professional team from the LFHC. Personal health information can be easily entered and printed by the patient. Although the patient decides what information to enter, ideally the Passport is created with a health care provider who can ensure accuracy of content and also provide an interactive educational experience. At the LFHC, Passports are most often prepared with a cardiac clinic nurse. The feedback from patients has been very positive. For example, one patient stated “Some of the stuff that was on it, I didn’t even know about myself until they told me to put it on the card.” Bookmarks explaining how to create a Passport are also available in the LFHC clinic waiting room and clinic rooms so that patients will have the information available to them for home use if they cannot create the Passport in the clinic.

A formal evaluation of patient experiences with the MyHealth Passport was recently published by Wolfstadt et al. [24]. In the first 16 months of availability, 742 patients (median age = 17 years) prepared Passports; 66% of these were SickKids patients. One hundred and ninety-nine patients completed online surveys immediately after creating their Passports, and 34 participated in telephone interviews. Patient feedback indicated that the Passport was easy to create and use, had an

Table 1
Summary of Toronto CHD transition task force initiatives.

Focus	Initiative
Educational Initiatives	MyHealth Passport
	Timelines
	Three-sentence summary
Initiatives focused on preparation for transfer	Patient and family education events
	Transfer posters
	Referral to Good 2 Go Transition program
	Transition evenings
	Individual pre-transfer tours
Initiatives targeting a coordinated transfer of care	iHeartChange website
	Transfer algorithm
	Patient transfer databases
	Transfer documents for patients and families
	Transfer letters for ACHD providers

educational element, facilitated communication with health care providers, and was carried by most users. The MyHealth Passport is available at no charge at www.SickKids.ca/MyHealthPassport.

3.2. Timelines

The Good 2 Go program created a disease-generic set of Timelines, entitled, “Help Them Grow... So They’re Good 2 Go [23].” The cardiac-specific Timeline was customized with feedback from the Task Force. The Timeline (prepared in poster and handout versions) highlights how a child with a cardiac condition can move along a developmentally appropriate continuum towards increased self management. The initial focus is on parents; however, as children grow and shift through various developmental stages, increased attention is directed towards them. Columns represent 5 age categories, 3 of which are directed at parents (birth to 3 years, 4 to 7 years, 8 to 11 years), and 2 of which are directed at patients (12 to 15 years, 16 years and older). Rows represent age-appropriate tasks that promote increased self-care and healthy development in 5 domains: general, social, self-care, education, and medical. Large poster-sized Timelines are placed in clinic waiting areas and exam rooms. In addition, handouts are given to each family at their first clinic appointment and reviewed at follow-up appointments. Items within the table are used to guide patient education, including but not limited to the knowledge of the patient’s health condition. In LFHC clinics, nurses manage this important educational component. For example, as patients move through adolescence, they are assisted to become better able to describe their diagnoses, surgeries and procedures, medications etc. One of the broad aims of the Timeline is to prompt families and health care professionals to envision the child’s future and assist them in taking a more active role in their own healthcare management. An evaluation of families’ perception of the usefulness of the Timeline is currently underway.

The cardiac Timeline has led to changes in regular clinical practice at the LFHC. For example, clinic nurses now typically speak independently with patients once they reach the approximate age of 13 years, though this varies in accordance with their developmental level. This gives patients the ability to learn to effectively ask and answer questions of their medical team [25]. It also allows them to discuss sensitive concerns without their parents present. The practice of adolescents and young adults with chronic conditions speaking independently with health care providers is supported by both patients and their parents [21,26]. Given that many physicians do not speak privately with patients with chronic conditions following transfer to adult care [27], the adult providers are also reminded of this practice.

3.3. The 3-sentence summary

The Task Force supports another Good 2 Go initiative, specifically the practice of the 3-sentence summary. At the LFHC, patients receive a bookmark outlining the 3-sentence summary: (1) age, diagnosis, and brief medical history, (2) treatment plan, and (3) question/concern to discuss in the clinic visit. The 3-sentence summary is consistent with the goals of empowering patients to become more knowledgeable of their heart condition and better able to communicate directly with health care providers [23]. This summary is introduced and practiced with LFHC clinic nurses.

3.4. Patient and family educational events

Patient and family education conferences have been held separately at the LFHC and TCCCA. Topics have included medical care and treatment, lifestyle matters (e.g., exercise, travel), parenting issues, and psychosocial concerns (e.g., preparing for cardiac procedures, effective communication). Though not exclusively focused on the needs of transitioning patients, such patient (and parent)

education is consistent with the aim of supporting patients to most effectively participate in their health care management. Each patient and family education conference at the LFHC, however, does have a transition-focused component. These are typically organized as break-out sessions such that patients and parents have separate sessions. Feedback has been positive and many parents of LFHC youth have expressed appreciation for preparation for transition and transfer.

4. Preparation for transfer

4.1. Transfer posters

Patients and families must be prepared in advance for transfer of care. One known predictor of successful follow-up at a specialized ACHD centre is documentation in the pediatric medical chart of the need for specialized CHD follow-up in adulthood [10]. It is recommended that pediatric providers have ongoing discussions with patients and families regarding care past the age of 18, but this might not always happen. Therefore, to ensure that transfer does not come as a surprise for any patient, there are posters in all SickKids clinic rooms that read: “At SickKids we prepare our patients to graduate to adult care. Don’t wait until you are 18 to start planning to leave. Talk with your health-care provider.”

4.2. Referral to the Good 2 Go transition clinic

Adolescents who are struggling with issues related to transition and/or transfer can be referred to the Good 2 Go Transition program, which has a weekly clinic for SickKids patients between the ages of 12 and 18. Concerns that prompt referrals often relate to difficulties with adherence, accepting their health condition, and/or becoming more autonomous. Members of the Good 2 Go program address complex psychosocial and/or medical factors that complicate a patient’s psychosocial development, transition through appropriate developmental stages, or transfer to the adult health care system. Nurses in the LFHC clinic refer an average of two patients each month to this clinic.

4.3. Transition Evenings

Transition Evenings began in 2002 with the nursing working group. They were conceived as an opportunity for the pediatric team to support the graduation of their patients and for the adult team to provide an introduction to their program. An initial barrier was difficulty identifying patients nearing the age of 18. Transition Evenings became more formalized in 2009, largely due to the creation of a searchable LFHC patient database. Promotional flyers were developed by the Task Force and are distributed in clinics and mailed to patients transferring within the year. The event is named: ‘Getting Ready for Adult Cardiac Care: An Information Night for Teens and Their Families.’ Flyers ask: ‘Have you wondered what it will be like receiving care for your heart at an Adult Clinic? This is your chance to find out.’ They are named Transition Evenings because they focus on patient knowledge and responsibility in addition to preparation for transfer. On average, 25 to 50 patients and family members attend each event, which are usually held twice a year.

The event, which lasts approximately 3 hours, begins at SickKids. This provides a familiar venue for patients and families and may also provide a sense of closure before venturing to the adult facility later in the evening. Patients and families are greeted by familiar faces of the pediatric clinic and members of the ACHD team. Each patient receives a transition packet with information about the adult facility, endocarditis prophylaxis, and travel information. The packet also includes a brochure from the Canadian Congenital Heart Alliance (CCHA; www.cchaforlife.org), which is the Canadian CHD patient organization. The first speaker is the LFHC Director, who offers parting words of encouragement and stresses the importance of continued

follow up to ensure optimal life-long heart health. The TCCCA Director then provides an official welcome to the adult clinic and discusses adult issues that are well served in the adult facility. The TCCCA nurse practitioner (NP), who is often the first point of contact for patients and families, then addresses the group. The NP explains how patients are transferred and the scheduling of the first clinic appointment. The final speakers are patients who have previously transferred to the adult program and/or members of the CCHA. All attendees then walk across the street for a tour of the TCCCA clinic and tips and information about the adult hospital. Questions from attendees are encouraged, which contributes to a very interactive evening. Attendees are often interested in learning about the culture of adult hospitals and differences between pediatric and adult clinics (e.g., the TCCCA does not have outpatient clinic nurses). They often appear reassured to learn of an experienced team of ACHD providers ready to take over their care. At the end of the evening, most family members express their appreciation to the event organizers. Patients and families are also given a survey to complete, for which the average overall rating of the event is 9 on a 1–10 scale.

4.4. Individual pre-transfer tours

Patients and families who are unable to attend a Transition Evening but are concerned about transfer are given the opportunity of a pre-transfer tour. These are coordinated through direct communication between Task Force members and are typically provided to patients with significant cognitive impairment and their families. While the ultimate goal of transition for majority of adolescents and young adults with CHD is to foster increasing responsibility for their health care management, the goals at the time of transition and transfer for cognitively challenged patients are focused on establishing a care partnership between the ACHD team and a patient's caregivers as well as formulating a common long-term care plan.

4.5. iHeartChange Website

Several members of the Task Force are part of a research team that developed and is now evaluating a website targeting the transition and transfer of adolescents with CHD from the LFHC to the TCCCA.

The iHeartChange website includes bios of TCCCA providers, a video introduction, and a map and photos of the outpatient clinic. Patients whose files have been transferred to the TCCCA are mailed personal user names and passwords for the iHeartChange website and are invited to participate in the research study.

5. A coordinated transfer of care

5.1. Transfer algorithm

To clarify the nature of referrals for all referring pediatric providers, the Task Force developed a transfer algorithm. The primary cardiac pathology determines the referral pathway because there are different subspecialty clinics that provide expert care for the different pathologies: CHD, arrhythmogenic right ventricular cardiomyopathy (CM), hypertrophic cardiomyopathy (HCM) and other CMs.

As presented in Table 2, the complexity of CHD determines the referral pathways. Adolescents with simple CHD or lesions with low care priority are referred to a community cardiologist. Adolescents with CHD of moderate or great complexity are transferred to a regional CACHNET center (<http://www.cachnet.org/centres.shtml>). The presence or absence of a pacemaker (PM) or automated internal cardioverter/defibrillator (AICD) also determines the referral pattern in Toronto. Patients with a PM/AICD and CHD or CM are referred to the Pacemaker/AICD clinic and also to the corresponding subspecialty clinic (ACHD, heart function, HCM). Adolescents with a PM/AICD, but without structural heart disease or CM are also intermittently assessed in the ACHD outpatient clinic in order to monitor myocardial function. The TCCCA clinic does not typically see patients with CM, but these referral pathways are also presented in Table 2.

5.2. Patient transfer databases

Accurate clinic databases are critical to ensure that patients are not 'lost' in this vulnerable period [1]. Prior to the formal establishment of the Task Force, it was obvious to members of the nursing working group that the number of LFHC patients reaching the age of transfer each year far exceeded the number of patients arriving at the TCCCA. At that time, there was no complete database available

Table 2
CHD transfer algorithm.

Referral destination	Cardiac condition
Transfer to a community cardiologist	<u>Lesions with low care priority</u> (1) Native, isolated valvular disease: • Mild mitral, aortic, pulmonary and/or aortic valvular stenosis/regurgitation (2) Simple CHD without hemodynamic impact, e.g., small atrial septal defect (with no dilatation of the right atrium/right ventricle and normal pulmonary-artery pressures), restrictive ventricular septal defect/patent ductus arteriosus (with no dilatation of the left ventricle and normal pulmonary artery pressures) (3) Repaired simple CHD defects without hemodynamic residual lesion or pulmonary hypertension: • Atrial septal defect closure (by surgery or device) • Patent ductus arteriosus closure (by surgery or device) • Ventricular septal defect closure (by surgery or device) (4) A family history of dilated CM, but normal myocardial function (5) Neuromuscular disorder without evidence of cardiomyopathy and/or rhythm disorder <u>All congenital heart defects with moderate or great complexity:</u> • Congenital heart defects named after a physician/surgeon • Surgical procedures named after a surgeon/physician • Conduits • Syndromes • Lesions at risk for heart failure / arrhythmias / re-intervention/pulmonary hypertension
Transfer to an ACHD Program: the TCCCA or another CACHNET centre	Dilated CM with an ejection fraction <40% Anthracycline side-effects and metabolic disorder associated with CM Neuromuscular disorder associated with CM or rhythm abnormalities Metabolic disorder with cardiomyopathy
Transfer to the heart function program at UHN or another regional centre with a heart function program	Hypertrophic CM Family history of hypertrophic CM
Transfer to the hypertrophic CM program at UHN	Metabolic disorder without evidence of cardiomyopathy; referral by the geneticist to an adult cardiologist/subspecialty clinic for screening and surveillance to occur as needed

in the clinic setting that could provide a list of patients reaching the age of 18. The first step was to educate all transferring pediatric cardiologists and their support staff of the process of referral and transfer of records. A LFHC transfer database was then created in order to more effectively track patients nearing the age of transfer. Support staff enters transfer details into this database after each clinic visit. The transfer algorithm assists clinic staff to ensure that patients are being transferred to appropriate adult care providers. For patients being transferred to the TCCCA, a list is faxed to the Administrative Program Coordinator on a bimonthly basis. In addition, the TCCCA has developed its own database to track newly-referred patients and ensure that appointments are booked accordingly.

5.3. Transfer documents for patients and families

Transfer packets are given to all patients at their last LFHC visit. The packet includes a pamphlet, developed by the Good 2 Go Transition program, entitled "Getting Ready for Adult Care." This pamphlet provides tips to promote effective patient-provider communication and preparation for their first adult hospital visit. As this Good 2 Go pamphlet is not CHD-specific, the Task Force also collaborated on a CHD-specific letter. The overall design of the letter ensures that patients and families recognize that there is a unified approach to their care (e.g., the letter contains logos of both SickKids and UHN). The letter first congratulates the patient on their graduation from pediatric care. A large TCCCA team photograph is presented on the first page, as is important information including the adult clinic's location, map, address, hours of operation, and contact telephone numbers. The letter emphasizes the importance of ongoing cardiac care with the ACHD program. Patients are reminded that the adult facility will ask them to assume a more active role in their care. The letter also encourages patients to discuss all concerns with their adult providers, including those less directly related to the heart condition, including exercise, smoking and alcohol, anxiety or depression, relationships, career planning and insurance, and family planning. Patients are urged to be ready to discuss their CHD and treatment history at their first TCCCA visit. A list of tests and procedures that patients may have the day of their first visit is included. Finally, this letter includes websites that patients and families might find helpful. The transfer packet also includes a CCHA brochure, MyHealth Passport information, and a graduation certificate.

After a patient's file is received at the TCCCA and coded by the Director, the booking office mails a welcome letter that includes the approximate month of the first appointment. In addition, the letter includes contact information and guidance should a cardiac issue arise before the first visit. A copy of this letter is also mailed to the LFHC provider to confirm successful transfer of the documents in order to 'close the loop.'

5.4. Transfer letters for ACHD providers

Following the final LFHC visit, the pediatric provider sends a referral to the adult clinic with details pertaining to the patient's surgical and/or interventional procedures, complications (arrhythmias, heart failure, endocarditis, etc.), medical management history and plan, and the need for endocarditis prophylaxis. Other documents in the referral packet include surgical notes, ECGs, any pertinent test results (e.g., diagnostic or interventional heart catheterizations, cardiovascular MRI, exercise tests), and recent and relevant clinic letters. Pediatric providers are requested to provide recommendations for specific diagnostic tests at the time of the first visit at TCCCA. Routine tests include ECG, CXR, TTE, and a cardiopulmonary study. Pediatric providers are also requested to provide a recommendation for the timing of the first adult clinic visit (e.g., to be seen in 6 months, 1 year, etc.). This transfer documentation assists the adult care providers to provide care that is guided by the medical providers most familiar with the patients.

The ACHD team requests additional information with the transfer of cognitively-challenged patients; this includes all relevant documents such as neurodevelopment or cognitive assessments and genetic testing results. These documents, in combination with information gathered at the first clinic visit, will assist the ACHD team to evaluate the patient and/or Substitute Decision-Maker's understanding of a patient's medical condition, prognosis, and life expectancy. The ACHD team prefers to formulate an individualized long-term care plan at the earliest stage possible. If short-term or intermediate surgical or catheter-based interventions are considered, all pre-intervention diagnostic tests will be performed in a well-coordinated manner to minimize hospital or test-associated distress. For example, one day each month is designated for diagnostic testing for adults with CHD under general anesthesia; an anesthesiologist, TCCCA staff member, imaging staff, the pre- and post-anesthesia care unit, and the cardiac short stay unit are all available on that day. If, however, a patient's SDM determines that no further invasive interventions are to be performed, the aim is to minimize diagnostic tests, emphasize the importance of preventive health care, and symptomatic management to preserve patient and family quality of life.

5.5. Initiatives not undertaken

There are initiatives that the Task Force chose not to undertake. As described, a Transition Coordinator is not currently available. In addition, the LFHC and TCCCA do not offer any type of 'transition clinics.' Joint transition clinics, attended by both pediatric and adult care provider, have been proposed so that pediatric providers can provide an introduction to future adult providers [28]. However, due to the large number (200+) of transferring patients each year and the large number of TCCCA cardiologists, this was deemed an impractical option. Further, adequate personnel are not available to consistently provide a formal transition clinic in either the pediatric or adult setting. However, if a patient has been identified as having extremely complex issues and needs, individual clinic appointments that involve both LFHC and TCCCA cardiologists can be arranged. The TCCCA has also intermittently held NP-run transition clinics for newly-transferred patients. Patients suitable for the transition clinic were identified upon receipt of their transfer documents. The transition clinic visit was scheduled 30 minutes prior to the first cardiology appointment; patients were given the option of including their parents. The discussion was tailored to each patient and often focused on medical, lifestyle, and/or psychosocial issues. It was an opportunity to identify ongoing educational needs and care strategies. The TCCCA hopes to eventually have the personnel to return to this practice.

6. Conclusions

The importance of a coordinated approach to transition and transfer is well-understood, although there are few models of comprehensive CHD transition programs. The Toronto CHD Transition Task Force, an interdisciplinary group of pediatric and adult providers committed to practical strategies to optimize the transition and transfer of adolescents and young adults with CHD, was convened in 2008. The Task Force has undertaken initiatives targeting patient and family education, preparation for transfer, and a coordinated transfer of care. This should not, however, be considered an exhaustive list of strategies. Rather, the Task Force undertook initiatives that reflect the needs and resources of the pediatric and adult CHD programs. It is hoped that that experiences of this Task Force will be of benefit to other programs wishing to develop or expand transition services.

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References

- [1] Saidi A, Kovacs AH. Developing a transition program from pediatric- to adult-focused cardiology care: practical considerations. *Congenit Heart Dis* Jul-Aug 2009;4(4):204–15.
- [2] Knauth A, Verstappen A, Reiss J, Webb GD. Transition and transfer from pediatric to adult care of the young adult with complex congenital heart disease. *Cardiol Clin* Nov 2006;24(4):619–29 [vi].
- [3] Hilderson D, Saidi AS, Van Deyk K, et al. Attitude toward and current practice of transfer and transition of adolescents with congenital heart disease in the United States of America and Europe. *Pediatr Cardiol* Aug 2009;30(6):786–93.
- [4] Sable C, Foster E, Uzark K, et al. Best practices in managing transition to adulthood for adolescents with congenital heart disease: the transition process and medical and psychosocial issues: a scientific statement from the American Heart Association. *Circulation* Apr 5 2011;123(13):1454–85.
- [5] Warnes CA, Williams RG, Bashore TM, et al. ACC/AHA 2008 guidelines for the management of adults with congenital heart disease: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Develop Guidelines on the Management of Adults With Congenital Heart Disease). Developed in Collaboration With the American Society of Echocardiography, Heart Rhythm Society, International Society for Adult Congenital Heart Disease, Society for Cardiovascular Angiography and Interventions, and Society of Thoracic Surgeons. *J Am Coll Cardiol* Dec 2 2008;52(23):e1–121.
- [6] Marelli A, Beaulac L, Mital S, Therrien J, Silversides CK. Canadian Cardiovascular Society 2009 Consensus Conference on the management of adults with congenital heart disease: introduction. *Can J Cardiol* Mar 2010;26(3):e65–9.
- [7] Deanfield J, Thaulow E, Warnes C, et al. Management of grown up congenital heart disease. *Eur Heart J* Jun 2003;24(11):1035–84.
- [8] A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics* Dec 2002;110(6 Pt 2):1304–6.
- [9] Steinbeck KS, Brodie L, Towns SJ. Transition in chronic illness: who is going where? *J Paediatr Child Health* Sep 2008;44(9):478–82.
- [10] Reid GJ, Irvine MJ, McCrindle BW, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics* Mar 2004;113(3 Pt 1):e197–205.
- [11] Wacker A, Kaemmerer H, Hollweck R, et al. Outcome of operated and unoperated adults with congenital cardiac disease lost to follow-up for more than five years. *Am J Cardiol* Mar 15 2005;95(6):776–9.
- [12] Beaulac LM, Therrien J, Alvarez N, et al. Structure and process measures of quality of care in adult congenital heart disease patients: a pan-Canadian study. *Int J Cardiol* 2012;157(1):70–4.
- [13] Mackie AS, Ionescu-Iltu R, Therrien J, Pilote L, Abrahamowicz M, Marelli AJ. Children and adults with congenital heart disease lost to follow-up: who and when? *Circulation* Jul 28 2009;120(4):302–9.
- [14] Yeung E, Kay J, Roosevelt GE, Brandon M, Yetman AT. Lapse of care as a predictor for morbidity in adults with congenital heart disease. *Int J Cardiol* Mar 28 2008;125(1):62–5.
- [15] Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics* Jan 2005;115(1):112–20.
- [16] Sawyer SM, Aroni RA. Self-management in adolescents with chronic illness. What does it mean and how can it be achieved? *Med J Aust* Oct 17 2005;183(8):405–9.
- [17] Hudsmith LE, Thorne SA. Transition of care from paediatric to adult services in cardiology. *Arch Dis Child* Oct 2007;92(10):927–30.
- [18] Moons P, Pinxten S, Dedroog D, et al. Expectations and experiences of adolescents with congenital heart disease on being transferred from pediatric cardiology to an adult congenital heart disease program. *J Adolesc Health* Apr 2009;44(4):316–22.
- [19] Van Deyk K, Moons P, Gewillig M, Budts W. Educational and behavioral issues in transitioning from pediatric cardiology to adult-centered health care. *Nurs Clin North Am* Dec 2004;39(4):755–68.
- [20] Goossens E, Stephani I, Hilderson D, et al. Transfer of adolescents with congenital heart disease from pediatric cardiology to adult health care: an analysis of transfer destinations. *J Am Coll Cardiol* Jun 7 2011;57(23):2368–74.
- [21] Shaw KL, Southwood TR, McDonagh JE. User perspectives of transitional care for adolescents with juvenile idiopathic arthritis. *Rheumatology (Oxford)* Jun 2004;43(6):770–8.
- [22] Boyle MP, Farukhi Z, Nosky ML. Strategies for improving transition to adult cystic fibrosis care, based on patient and parent views. *Pediatr Pulmonol* Dec 2001;32(6):428–36.
- [23] Amaria K, Stinson J, Cullen-Dean G, Sappleton K, Kaufman M. Tools for addressing systems issues in transition. *Healthc Q* 2011;14:72–6.
- [24] Wolfstadt J, Kaufman A, Levitin J, Kaufman M. The use and usefulness of MyHealth Passport: an online tool for the creation of a portable health summary. *Int J Child Adolesc Health* 2011;3(4):499–506.
- [25] Transition to adult care for youth with special health care needs. *Paediatr Child Health* Nov 2007;12(9):785–93.
- [26] Hutchinson JW, Stafford EM. Changing parental opinions about teen privacy through education. *Pediatrics* Oct 2005;116(4):966–71.
- [27] Suris JC, Akre C, Rutishauser C. How adult specialists deal with the principles of a successful transition. *J Adolesc Health* Dec 2009;45(6):551–5.
- [28] Kennedy A, Sloman F, Douglass JA, Sawyer SM. Young people with chronic illness: the approach to transition. *Intern Med J* Aug 2007;37(8):555–60.