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REVIEW ARTICLE

WILEY Congenital Heart Disease

# Improving the quality of transition and transfer of care in young adults with congenital heart disease

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## Abstract

The transition and transfer from pediatric to adult care is becoming increasingly important as improvements in the diagnosis and management of congenital heart disease allow patients to live longer. Transition is a complex and continuous process that requires careful planning. Inadequate transition has adverse effects on patients, their families and healthcare delivery systems. Currently, significant gaps exist in patient care as adolescents transfer to adult care and there are little data to drive the informed management of transition and transfer of care in adolescent congenital heart disease patients. Appropriate congenital heart disease care has been shown to decrease mortality in the adult population. This paper reviews the transition and transfer of care processes and outlines current congenital heart disease specific guidelines in the United States and compares these recommendations to Canadian and European guidelines. It then reviews perceived and real barriers to successful transition and identifies predictors of success during transfer to adult congenital heart disease care. Lastly, it explores how disease-specific markers of outcomes and quality indicators are being utilized to guide transition and transfer of care in other chronic childhood illnesses, and identifies existing knowledge gaps and structural impediments to improving the management of transition and transfer among congenital heart disease patients.

**KEYWORDS**
congenital heart disease, lost to follow-up, transfer of care, transition

## 1 | INTRODUCTION

The improved survival of patients with diseases historically associated with childhood mortality, including congenital heart disease (CHD), cystic fibrosis, pediatric malignant neoplasms, sickle cell disease and cerebral palsy, has led to recognition of the need for transitional care for the adolescent and young adult patient.[1] In all of these diseases, physiological changes of puberty occur within the setting of behavioral change as adolescents struggle for greater autonomy and independence. A well-structured transition from pediatric to adult care is essential to appropriately address disease management as these patients navigate the same transition to independence and productive adult life as their peers without chronic illness.

Patients with CHD comprise a substantial subset of pediatric patients with special healthcare needs, forming the largest group of congenital anomalies.[2] As recently as several decades ago, few patients with severe lesions survived into adulthood. Advancements in cardiac surgery and interventional cardiac catheterization have drastically improved longevity of CHD patients, and consequently the congenital heart disease management is shifting to include adult-oriented care. As the median age of people with severe CHD has increased from 11 years in 1985 to 25 years in 2010,[3] CHD is transforming from a life-threatening childhood illness to chronic adult illness.

The overall incidence of CHD in the United States has been estimated as 8 per 1000 live births,[4] and has a prevalence of approximately 3-4 cases per 1000 adults.[5] Because ~90% of children with congenital heart disease survive to adulthood, adults have comprised the majority of documented CHD cases since 2010, with an estimated 1.4 million adults in the United States living with CHD.[6] This represents a 63% increase in the estimated number of adults with CHD in the United States since 2000.[6]

Survival of adults with CHD differs by severity of lesion, with the 10-year survival among adults with simple, moderate and complex CHD estimated at 95%, 90% and 80%, respectively.[7] Recent evidence

  

**TABLE 1** Common comorbidities in adult patients with CHD and impact on outcomes

| Comorbidity | | Impact on CHD outcomes |
|---|---|---|
| Cardiovascular disease | Arrhythmia<br>Atherosclerotic disease<br>Heart failure | Hospitalization[68,69]<br>Functional status[12,69]<br>Mortality[69]<br>Need for re-intervention[68]<br>Quality of life |
| Hepatic | Congestive hepatopathy<br>Hepatitis C | Fontan-associated liver disease[70,71]<br>Mortality |
| Neoplasms | Catheter- and imaging-related radiation | Mortality |
| Psychosocial | Anxiety<br>Depression<br>Neurocognitive delays<br>Post traumatic stress disorder | Maintenance of care[72]<br>Medication adherence[73]<br>Quality of life[12,72,74,75]<br>Neurocognitive decline[43] |
| Pregnancy | Contraception-related CV Risks<br>Maternal CV risks<br>Obstetric risks<br>Offspring risks | Fetal mortality[11,76–78]<br>Premature birth[11,76–78]<br>Small-for-gestational-age infants[11,76–78]<br>Mortality[11]<br>Neonatal CHD<br>Thromboembolic events[12]<br>Cardiovascular events[11,76–79]<br>Hospitalization, quality of life |
| Pulmonary | Restrictive lung disease | Functional status<br>Mortality[80] |
| Renal | Renal failure | Hospitalization[68]<br>Mortality[81,82] |

suggests that contemporary survival of patients with mild lesions does not differ from the general population, with a median survival of 84.1 years, while the median survival of patients with moderate and severe lesions is significantly shorter, at 75.4 and 53.4 years, respectively.[8] The accuracy of modern imaging diagnosis and the improvement of surgical techniques and postoperative care have contributed to the observed increase in patient survival.[9,10]

As patients with CHD age, they acquire noncardiac comorbidities that are more familiar to internists than to pediatricians. Because congenital heart disease is generally noncurative, the management of adult congenital heart disease (ACHD) patients is complicated by cardiac and hemodynamic complications, a need for reproductive counseling, and adult comorbidities.[11–13] Patients with CHD experience an increased prevalence of genetic syndromes with multisystem involvement requiring multispecialty management. Genetic syndromes, cyanosis and cardiopulmonary bypass all increase the risk of neurodevelopmental delays, such as executive functioning and attention deficits[14,15] that may present in adolescence[16] and affect successful transition into adult care. Common comorbidities present in ACHD patients are outlined in Table 1.

Despite a high prevalence of complicated cardiac anatomy combined with significant adult comorbidities, fewer than 30% of adults with CHD are appropriately followed by specialized providers, while only 48% of adolescent patients with CHD underwent successful transfer to adult care.[17] This evidence suggests that extensive opportunities exist to develop deliberate, ongoing and coordinated transition and transfer of CHD patients from pediatric-centered to adult-centered care, guided by professional guidelines and recommendations. It is essential that adolescents with CHD become familiar with the details of their disease, as well as future complications, medications, management and other CHD-related issues as they transition through adolescence into adulthood and gain increasing autonomy and independence from their parents.

## 2 | TRANSITION AND TRANSFER: AN OVERVIEW

Transition refers to the complex and continuous process of preparing a patient to change from pediatric-centered care into adult-centered care in a purposeful, planned and timely manner.[18,19] Transition includes the identification of an adult-centered practitioner and preparing the patient to independently navigate the adult health system.[18] In contrast to transition, "transfer of care" refers to the actual point in time at which responsibility for the patient's care is shifted from the pediatric to the adult provider.[19] For congenital heart disease patients, we define successful transfer of care as establishment of care with a trained adult congenital provider. This provider may have initially trained in pediatric cardiology or adult cardiology, but should have finished additional training in the care of adults with congenital heart disease.

In 2011, the American Academy of Pediatrics (AAP), American College of Physicians (ACP) and American Academy of Family Physicians (AAFP) released a joint series of recommendations supporting transition from adolescence to adulthood in the medical home. These organizations recommend that the transition process start at age 12 years old and finish with transfer of care between 18 and 21 years old. The AAP outlined successful transition and transfer of care as a maximization of life-long functioning and well-being, and concluded that transition

planning should be a standard part of providing care for all youth and young adults, with every patient having an individualized transition plan regardless of specific healthcare needs.[18]

An ideal transition program promotes control over health and healthcare decisions, and fosters patient independence to maximize productivity and quality of life. It will also foster patient skills in communication, decision-making, self-care and self-advocacy while providing uninterrupted healthcare that is age and developmentally appropriate.[20–23] Self-care is as an important component of chronic disease management, and lower levels of self-care have been associated with poor health outcomes, making it an important factor to be considered when designing structured transition programs. It is especially important that the adolescent is educated on their own cardiac diagnosis while they are learning how to be self-advocates prior to transfer to the adult healthcare system.

Inadequate transition planning has adverse effects on patients, their families, and healthcare delivery systems. Patients and families who do not receive transition planning may encounter delayed transfer to adult-centered care, increased financial and emotional burden, and inappropriate care resulting in patients who are lost to follow-up, patients who use less care, and patients who use more care than they would need given their functional status.[24] Every effort should be made prior to transfer of care to identify the care setting that will best meet an individual patient's needs, and thus avoid placing undue strain on patient, family and healthcare system resources.

Despite the importance of appropriate transition to adult care, the process continues to challenge providers who care for patients with special needs who age out of the pediatric care system. There are an estimated 4.5 million (18.4%) youth aged 12-18 requiring special healthcare needs in the United States, of whom just 41% received transition-oriented services to adult healthcare as established by the Department of Health and Human Services' (DHHS) Maternal and Child Health Bureau.[25] With its inclusion in Healthy People 2020, transition of care has been recognized by the federal government as a key component of nationwide health promotion and disease prevention strategies.[26]

Ideally, a transition program consists of a healthcare team including nurses, social workers, care coordinators and both pediatric and adult physician champions.[27] The development of ideal transition programs may not be feasible in the current healthcare environment in the United States due to the lack of universal insurance coverage for young adults, but continued implementation of structured transition and transfer processes will likely continue to play an important role in improving healthcare and quality of life as chronic disease burdens continue to shift from children and adolescents to adults.

## 3 | GUIDELINES FOR THE TRANSITION AND TRANSFER OF CONGENITAL CARDIOLOGY PATIENTS

European and Canadian guidelines recommended transition programs with transfer of care by 18 years old prior to the initial American ACHD guidelines in 2008.[28] In 2011 the American Heart Association (AHA) released a series of recommendations reinforcing the AAP, ACP and AAFP guidelines published earlier that year. These included recommendations regarding the inclusion of the patient, parents and family in the transition process; the role of primary care and medical follow-up; residual cardiac and noncardiac surgeries; anticipatory guidance of genetic counseling, pregnancy and reproductive issues; counseling regarding exercise, education, career choices, insurance and end-of-life care.[19]

Among the most significant recommendations made by the AHA are those regarding the timing of transition. Emphasis should be placed on individualized transitional processes that account for a patient's developmental age, as well as how chronic illness and congenital heart defects impact normal developmental milestones. Ideally this process should start in early adolescence at age 12 and conclude with transfer of care by 21 years old. The guidelines also stress continuous coordination of services between regional ACHD centers and pediatric and primary care providers. It is also imperative to address multiple behavioral, emotional and quality of life issues that are more prevalent in adolescents with CHD than in other adolescent populations.[19] "Got Transition" (www.gottransition.org) in the United States and "Ready Steady Go" (http://www.uhs.nhs.uk/readysteadygo) in the United Kingdom provide templates to set up transition programs.[27,29]

At the time that these guidelines were released, many pediatric cardiologists provided care to adults and were hesitant to transfer age-appropriate patients to ACHD specialists. Reasons for referral of ACHD patients by pediatric cardiologists to ACHD specialists is primarily driven by adult comorbidities, even in settings that have ACHD programs.[30] Perhaps paradoxically, pediatric cardiologists are more likely to hold discussions regarding transfer of care with younger patients with simple CHD more often than with complex patients.[31]

Adult patients may benefit by receiving care from adult-trained congenital heart providers, although data examining clinical health outcomes is lacking, and most research into the transition from pediatric to adult health services in CHD examine loss to follow-up and gaps in care as primary outcomes. However, it is clear that the need for adult consultation services will continue to increase as ACHD patients age and develop more complex comorbidities; a review of ACHD admissions in pediatric hospitals revealed that 30% had comorbid conditions requiring subspecialty care.[32] In Canada, where there is a mandatory transfer of care out of the pediatric system, ACHD patients are seen by adult cardiologists with or without congenital training. The publication of Canadian guidelines endorsing specialized ACHD care was found to precede a significant increase in referrals to ACHD centers, which was independently associated with a significant mortality reduction.[33] This evidence suggests that care in specialty CHD centers, which constitutes the ideal outcome of the transition and transfer of care processes, may have significant effects on the mortality of CHD patients.

Despite a lack of patient health outcomes data to guide CHD transition and transfer of care guidelines, adult congenital cardiologists comply with health maintenance recommendations in the ACHD

patient population better than either their general adult cardiologist or pediatric cardiologist colleagues. Training determines cardiologist practice style; adult cardiologists are better at documenting substance abuse and lipid screening, whereas pediatric and adult congenital cardiologists document endocarditis prophylaxis and exercise recommendations better than adult cardiologists.[31] Adult congenital providers are the most well-rounded and perform contraception or pregnancy counseling more frequently than other cardiologists.[31] Mylotte et al. demonstrated improved outcomes among ACHD patients managed by cardiologists who specialize in adult congenital care rather than by general adult cardiologists.[33]

Ultimately, the guidelines for ACHD care recommend that all young adults with CHD receive at least one assessment at an ACHD center to determine the level and frequency of long-term care required. Over half of these patients will need active management at a regional ACHD center and the remainder should be seen by a cardiologist with a referral relationship with an ACHD center.[7] Although patients should see an ACHD physician, during the first American Board of Internal Medicine ACHD board exam, only 195 physicians became board certified in 2015,[34] and current training pathways take 8 to 9 years to complete after medical school.[35] As the ACHD population increases, the ACHD physician workforce may not keep up with the demand.

It is difficult to find the perfect setting to care for ACHD patients since they require specialized imaging, interventional, heart failure, electrophysiology and surgical teams but also access to adult subspecialty providers.[7] Balancing subspecialty care against age-appropriate care is difficult, and it is not yet clear whether the role of pediatric hospitals in the healthcare system will be to provide care for children only vs. all patients with chronic diseases of childhood. In the United States, strong ACHD centers have developed from both pediatric and adult cardiology programs depending on the access to resources and support. The different ACHD centers may have different obstacles to successful transition and transfer of care depending on their setting. Despite these differences, it is important to have good communication between pediatric and adult congenital providers, as well as invested stakeholders from both groups.

## 4 | PERCEIVED BARRIERS TO TRANSFER OF CARE

Seamless care of young adult CHD patients requires careful examination of barriers that may interfere with a smooth transition process and the transfer of care. The proportion of CHD patients admitted to the emergency department nearly doubles around the age of transfer to adult care, suggesting significant comorbidity and discontinuity of care.[13,36] There are many barriers to successful transfer of care, both real and perceived, that may be organized into structural, institutional, social and neurocognitive domains. These barriers are summarized in Table 2. The process is further complicated by the necessary involvement of multiple key stakeholders in the transition process—providers, patients and their parents—each of whom may identify a different set of barriers in the transfer of care process.

Structural barriers to successful transfer to adult-oriented care refer to systemic medical practices, and include decreased insurance availability for adult-oriented healthcare, limited resources for the education and training of subspecialty healthcare providers, and the potential need to transfer to another healthcare system for adult CHD care.[37,38] Both pediatricians and internists cite lack of reimbursement for time and coordination of care during the transition process as a major barrier to successful transfer.[39] Patients and providers also encounter barriers to transfer implemented at the institutional level. Providers often cite provider-patient attachment and concern regarding patient self-advocacy and knowledge as major barriers to transfer of care. Emotional attachment and a perceived lack of adult subspecialty providers are frequently cited by both patients and parents as barriers to transfer.[40,41]

Neurocognitive development has also been implicated as a barrier to acquire skills needed during transition in CHD patients. While children with complex CHD are more likely to have mild reduction in cognitive performance and impaired executive function,[42] few studies have addressed the translation of these findings to neurocognitive function in the adolescent and adult with CHD. Neurodevelopmental delays (social, emotional and executive functioning) may contribute to poor compliance with surveillance during the transfer period.[43]

**TABLE 2** Barriers perceived by patients, families and healthcare providers to interfere with the transfer of adolescents with CHD from pediatric to adult care

| Domain | Perceived barriers |
|---|---|
| Structural[37–39] | Insurance availability<br>Subspecialty healthcare training and education<br>Interinstitutional transfer<br>Lack of reimbursement for transition visits and care coordination |
| Institutional[30,83–85] | Lack of formal transition programs<br>Lack of ACHD provider availability and training<br>Institutional aging-out policies<br>Lack of primary care physicians and hospitalists comfortable caring for CHD<br>Complex navigation |
| Social[17,52,86] | Provider-patient and provider-parent attachment<br>Patient self-advocacy and knowledge<br>Parental involvement |
| Neurocognitive[43] | Developmental delays<br>Disability in social, emotional, executive function domains |

A Barriers to Care Questionnaire (BCQ) has been developed and validated in vulnerable children with asthma.[44,45] The BCQ classifies barriers to care into five categories—pragmatics, skills, expectations, marginalization and knowledge and beliefs. A higher BCQ score correlates with fewer barriers, and provides a way to quantify barriers of care. Although to date, no studies have been identified that explore CHD-related barriers to care using a standardized, internally consistent, and validated instrument, there are multiple transition readiness tools that can be applied to all young adults with chronic disease of childhood.[27,29] The transition readiness assessment questionnaire (TRAQ) is a validated example of a transition tool.[46] So far, these tools have not been shown to lead to significant improvement in clinical outcomes.[47]

## 5 | PREDICTORS OF SUCCESSFUL TRANSFER OF CARE IN CHD PATIENTS

In addition to managing the barriers encountered by CHD patients, families and providers, effective transition programs must recognize patient-specific factors that predict successful transfer of care. Little research has been identified that examines predictors of successful transfer from pediatric to adult care among CHD patients,[17,37] although multiple studies have identified factors associated with loss to follow-up or gaps in care during the transition and transfer process.[48–51] Ultimately, further research will be necessary to elucidate factors that correlate most strongly with successful transition and transfer, as well as loss to follow-up or lapses in care among CHD patients (Table 3).

Determinants of successful transfer to adult-oriented care include sociodemographic factors, patient beliefs, patient medical history and health status, and parental involvement. Reid et al.[17] found that successful transfer to adult care in Canada was not related to patients' age, gender, educational attainment, residence in parents' home or average family income. It should be noted, however, that patients in the United States likely face increased barriers to transfer of care as a result of insurance status[37] and socioeconomic status. Decreased median family income has been associated with attrition from follow-up in adolescents prior to transfer,[50] and low socioeconomic status likely contributes to loss from follow-up through a greater relative direct cost burden of healthcare among low-income patients, as well as increased transportation and opportunity costs.

Patient beliefs regarding their condition have been identified as important predictors of successful transfer of care. Patient beliefs that follow-up care should occur at an ACHD center, perception of high risk of CHD complications and belief that follow-up should occur annually have been associated with improved likelihood of successfully presenting to ACHD care.[17]

Documentation in the medical record of the need for cardiac follow-up with ACHD care is an important predictor of successful transition, as recommendation by the pediatric cardiologist for ACHD follow-up is associated with 9.3 times greater odds of successful transfer.[17] This likely reflects communication between the cardiologist, patient and parent regarding the importance of follow-up. Lack of patient awareness of the need for follow-up is cited as the most common cause of gaps in care among ACHD patients, and when combined with institutional appointment scheduling limitations, may result in failure to ever book a follow-up appointment.[52]

Patient health status and prior medical history is also an important determinant to successful transfer or potential lapse in care. Increased frequency of pediatric cardiovascular surgeries, the presence of comorbid conditions and limitations in physical function, CHD symptoms, dental prophylaxis and patient beliefs regarding where and when adult

**TABLE 3** Determinants of successful transfer from pediatric to adult care and loss to follow-up among CHD patients

| | Association | |
|---|---|---|
| **Determinants** | **Successful transfer** | **Loss to follow up/care gap** |
| Sociodemographic | Older age at last pediatric visit[17]<br>Insurance status[37]<br>Presence of a medical home[87] | Male sex[17,48,49]<br>Last cardiology visit outside a university hospital setting[49]<br>Decreased median family income[50]<br>Increased distance from clinic[88] |
| Patient beliefs | Recommendation from pediatric cardiologist for ACHD care[17,37]<br>Belief that follow-up should be at ACHD center[17]<br>Belief that follow-up should occur annually[17]<br>Perceived high risk of CHD complications and not attending cardiology appointments[17] | Lack of awareness of the need for follow-up[52]<br>Feeling well[53] |
| Medical history | Increased frequency of pediatric cardiovascular surgeries[17]<br>Frequency of adolescent cardiac appointments[17] | No prior cardiac surgery[48]<br>Fewer visits to a cardiologist[49]<br>Fewer visits to a noncardiologist[49]<br>One or more missed cardiology appointments[50] |
| Health status | CHD symptoms[17]<br>Comorbid health conditions[17]<br>Activity restrictions[17]<br>No significant alcohol or drug use[17]<br>Dental antibiotic prophylaxis[17] | AHA Class II compared with Class III[52]<br>Simple shunt lesion compared with a severe lesion[49]<br>Residual hemodynamic lesion on echocardiogram[88] |
| Parental involvement | Attending pediatric appointments without parents[17] | Living independently from parents[52] |

follow-up should take place have been associated with successful transfer among CHD adolescents.[17] The complexity of CHD lesion and functional status has also been correlated to patient proclivity to leave care for a longer period of time than recommended.

The relationship between parental involvement in care and successful cardiology follow-up is not yet fully elucidated. Adolescent attendance at pediatric appointments without parents has been associated with successful transfer to adult care, while patients who live independently from their parents have been shown to have four times greater odds of experiencing a lapse in care.[17,52] While parental independence is important in fostering the transfer of adolescent CHD patients into adult-centered care, at least some degree of involvement by parents in their child's healthcare is necessary to maintain long-term continuity of care.

Among CHD patients who have successfully transferred into adult care, a lapse in medical care may result in adverse outcomes, including the need for urgent cardiac intervention.[52] Patients, regardless of anatomic CHD complexity, indicate that feeling well is a major contributor to leaving care, highlighting that providers cannot rely on symptomatology to drive these patients to remain in appropriate care.[53] Return to cardiology care is most often precipitated by a desire to prevent potential problems, recommendation from another healthcare provider, or development of new symptoms or health problems.[53]

## 6 | DISEASE-SPECIFIC CLINICAL OUTCOMES IN NON-CHD TRANSITIONAL CARE

Structured transition programs have become widely proposed and implemented in recent years for the care of young adults with a variety of pediatric-onset diseases, including CHD, type 1 diabetes mellitus (T1DM), cystic fibrosis (CF), irritable bowel disease (IBD) and urologic disease. Most data regarding transition and transfer from pediatric to adult care up to this point have examined qualitative barriers and predictors of successful transition; there is little data systematically examining disease-specific clinical outcomes in transitional care.

As of 2011, systematic review identified just four evaluation studies of transition clinics in which both pediatric and adult care providers are involved in the delivery of outpatient care in preparation for transfer of care.[54] By 2016, a Cochrane review only identified four small studies that evaluated outcomes for transition programs.[47] Additional evaluations have since been published in a variety of fields, including epilepsy, IBD and kidney disease, although few look at disease-specific clinical outcomes.[55,56] However, evaluation of structured transition and transfer programs in CF and T1DM clinics have become increasingly focused on disease-specific clinical outcomes in recent years. Randomized controlled trials are currently underway to explore the impact of transitional programs on the clinical course of patients with these diseases.[57,58]

Structured transition and transfer programs have been implemented extensively in adult CF clinics in recent years,[59] as the Cystic Fibrosis Foundation requires clinics that treat more than 40 patients over the age of 21 to have a formal plan in place for the transfer of patients into adult care to receive accreditation as a CF Care Center.[59,60] Evaluation of the transition process in patients with CF has revealed that patients that do not undergo transition prior to transfer have a greater decline in clinical outcomes, including FEV and BMI.[61,62]

It has also been shown that transition support programs improve the quality of care in adolescents with T1DM. Systematic review of the effectiveness of various transition programs identified patient education programs and joint pediatric/adult clinics as services that may improve outcomes in adolescents with T1DM.[54] Although the comparative benefits of these programs have not yet been elucidated, structured transition and loss to follow-up during the transfer period have been associated with significant effects on glycemic control and diabetes-related complications.[63–65] Currently a multicenter randomized control trial is being conducted to determine whether structured transition programs improve diabetes clinic attendance and glycemic control after the transfer to adult diabetes care.[57]

Major gaps in knowledge relating to transition and transfer from pediatric to adult-oriented CHD care that have been identified including the lack of a standardized quality improvement tool, patient access to care, insufficient data supporting predictors of successful transition and transfer in CHD patients, and inadequate data examining disease-specific quality indications. The majority of research into barriers of successful transition and transfer of the young CHD patient has utilized questionnaires and surveys targeting providers, patients and parents in an attempt to identify perceived barriers. To date, no standardized instrument has been developed that could be used as a benchmarking tool in the quantification of CHD barriers of care. Unlike hemoglobin A1C in T1DM and FEV and BMI in CF, one particular metric does not apply for all types of CHD. Gurvitz et al. propose specific quality indicators of 6 different diagnoses. For example, the authors propose advanced imaging of the aorta every 5 years for patients with coarctation. Most of these quality indicators are focused the structure and process and do not look at outcomes.[66] There is also little existing data examining disease-specific clinical outcomes of formal transition and transfer programs. Currently, a single randomized trial has been identified that aims to evaluate the efficacy of a nurse-led transition program among adolescents with CHD and the subsequent need for re-intervention.[67] As similar changes are pushed for in the care of young adults with CHD, it will remain crucial that the formal, guided transition processes implemented by CHD centers are closely examined for the impact of these programs. This may be challenging due to the heterogeneity of the CHD population, with unique quality indicators best suited to guide the management of these patients. Identified opportunities to optimize the transition process for young CHD patients are outlined in Table 4. In our experience, many patients fail to complete successful transfer despite guidelines and often have significant gaps in care. Advocacy and improved awareness for continued care redirects patients who have fallen out of care to appropriate providers. In the future, telemedicine may improve access to ACHD care to remote regions.

**TABLE 4** Opportunities to minimize barriers to care, fill in knowledge gaps, and increase successful transition and transfer of care among CHD patients

| Transition and transfer future directions |
|---|
| 1. Identification of easily reportable quality indicators or outcome for quality care |
| 2. Increase training opportunities for ACHD providers |
| 3. Education of adult providers and subspecialist on long-term complications of CHD and the importance of continued care |
| 4. Evaluate transition and transfer of care programs including sequencing of topics |
| 5. Create Barriers to Care Questionnaire for CHD |
| 6. Emphasize the need to continue cardiac care throughout life |
| 7. Reduce structural and institutional barriers to care |
| 8. Advocate for improved reimbursement for transition programs |
| 9. Implement transition readiness assessments |

## 7 | CONCLUSIONS

The average lifespan of patients with CHD continues to increase with improved diagnosis and treatment of CHD, and in recent years the number of adults with CHD have surpassed children with CHD. While the importance of transitional care for the adolescent and young adult CHD patients has become increasingly recognized over the past several decades, recent evidence has highlighted extensive opportunities to develop coordinated transition and transfer processes for CHD patients.

As the transition and transfer of care process is further refined for CHD patients, it will also be important to increase training opportunities for ACHD providers, educate generalist and subspecialist providers on long-term complications of CHD, minimize institutional and structural barriers to care, and emphasize the need to for life-long continuous cardiac care to patients.

### CONFLICT OF INTEREST

None.

### AUTHOR CONTRIBUTIONS

*Contributed to paper design and final approval prior to submission*: Everitt, Gerardin, Rodriguez, Book

*Drafted the initial paper*: Everitt

*Critically revised the paper*: Book, Gerardin, Rodriguez

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