

Transition Medicine in Pediatric Cardiology

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CHD encompasses multiple different diseases, ranging from mild to severe. Many children born with complex CHD who previously would have died at an early age are now surviving into adulthood. Advances in medical and surgical care for CHD children have resulted in ~85% survival into adulthood and there are now roughly 1.4 million survivors of CHD reaching adulthood. However, despite improved treatments, CHD survivors are often palliated rather than cured. As such, lifelong surveillance and disease management are critical to maintain healthy and productive lives.

Poor transition and transfer of care significantly and adversely affect health outcomes for CHD adolescents, particularly minorities. CHD adolescents have unique medical, social, emotional, and functional needs throughout their lives. As such, a successful transition from pediatric to adult care is critical to reduce lapses in care.

Transition is a multifaceted process for adolescents with CHD, and needs to be understood from five different perspectives: the patient, the parents, the pediatrician, the pediatric cardiologist, and the adult cardiologist. In addition, the aspects of developmental progression and the impact of their chronic illness on adolescent and family development have to be fully incorporated. Major developmental milestones (e.g. self-care, social interaction) typically achieved during adolescence are often disrupted and underdeveloped in children with a chronic illness such as CHD. Furthermore, information transfer from pediatric to adult cardiologist is often lacking or incomplete. Transition- and transfer-related intervention efforts have largely failed to address this multifaceted process for chronic-disease adolescents. Studies show that <30% of adults with CHD are seen by appropriate specialized congenital heart physician providers, and that many have lapses in care. These lapses of care translate into a higher likelihood of needing an urgent surgical or catheter-based intervention. Transition outcomes are particularly suboptimal among ethnic minorities

At TCH, we have created a transition program for adolescents and young adults with CHD between the ages of 15 and 21 years. This program was created by using transition medicine guidelines, best practices for pediatric cardiology transition, and understanding the needs of stakeholders, including the patient, their parents, and the medical providers (pediatric cardiologists, adult CHD specialists, and the pediatric and adult primary care physicians). The program incorporates our transition education and skill training into the pediatric cardiology clinic, with the transition team introducing the program to CHD families at 14 years of age. Starting at 15 years, the transition team meets independently with the adolescent with CHD and administers a CHD knowledge and transition skills assessment. A thorough formal needs assessment is then conducted, including collecting information about their understanding of navigating the medical system, their mental health and coping skills, their understanding of health insurance, and their understanding of living with CHD (including risky behaviors, recognizing medical emergencies, and the need for long-term follow-up). Based on this data, the transition team creates an individualized learning plan (ILP) for each patient, tailoring their education to suit their knowledge and skill deficits. This information is

CHHATT: Congenital Heart Health Activation Transition Tool



STEP 1 Emergency Management	What is my Three Sentence Summary? How and when would I use it to explain my condition? 1. My name is _____ and I am _____ years old. 2. My heart condition is _____ and I was _____ with _____ 3. My condition specific emergent or urgent symptoms are: _____ _____ _____			GOOD FOR ME	BAD FOR ME
				Activities	Restrictions
				Diet	Avoid
STEP 2 Basic Management	My meds are:	I take them for:	What am I doing every day to manage my condition? Having good oral hygiene is important for my heart health. I _____ _____ need antibiotics before I go to the dentist. Avoiding high risk behaviors is also important! High risk behaviors for me are: _____ _____ Some CHD patients have traveling risks. What I need to know about traveling is: _____		
				Coping Skills	Red Flags
STEP 3 Trajectory and Lifelong Management	What will my disease look like in the future? How will I best manage it?				
	My doctor and I have discussed the following possible long-term issues associated with my heart condition: _____ _____ _____	These are the things I need to do every year to protect my heart: _____ _____ _____ _____	My risk of passing on my heart condition to my children is: _____ _____ If I become pregnant or want to have a baby, I should talk to my cardiologist right away. I don't need to be shy about starting a conversation with my doctor about heart disease and my sex life.	As an adult with a CHD, I will need to know: My Advance Directives are _____ My insurance is _____ and I am covered until I am _____ My plan for continued coverage includes: _____	
This conversation will help to evaluate the significance of your condition in your everyday life!					

Figure 51-1. Transition team “chalk talk”.

then entered into an adolescent database and a special section of the electronic medical record that we created for the purposes of a) tracking potential improvements in CHD knowledge and transition skill acquisition with each transition team encounter, and b) providing that information to the pediatric cardiologist caring for the patient.

The transition team uses a 3-sentence summary format to help our patients better understand their condition (primary diagnosis or disease), their treatments (procedures, surgical repairs, medications, and the importance of compliance), and their disease trajectory (symptoms that may require emergent care and how to self-monitor) (Figure 51-1).

Confidence in communicating their condition is important to all patients; however, it can really help young adults establish independence. Thus, beyond educating on their disease process, the transition team teaches adolescents with CHD transition skills (making their own appointments, asking the physician questions directly, etc.), provides important medical system navigation resources (“MyChart”), and helps with coping strategies (to deal with stress, anxiety, etc.).

The team also covers challenging topics including birth control, high-risk behaviors, and activity restrictions. The team provides referral information for adult cardiologists specializing in CHD, subspecialty providers trained to work with CHD patients (e.g., obstetricians and gynecologists, gastroenterologists), and additionally teaches about insurance, future career, and family planning.

PART III. SPECIAL CONSIDERATIONS

An adult planning visit happens at the 18-year-old pediatric cardiology visit, and includes discussion with the transition team, parent, patient, and pediatric cardiologist. This visit includes a formal recommendation for following to an adult congenital heart physician, discussion of an advanced directive, a formal transfer summary, and discussions of other ways to empower the young adult with CHD. As individual needs are met and transition skills are gained, the adolescent continues at each visit to meet with the transition team until they are ready for transfer to adult care. Official policy at TCH includes transfer to adult CHD care at 21 years of age.

Suggested Readings

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