Teens With CHD Need Tailored Transition Care

BY HEIDI SPLETTE
FROM CIRCULATION

The transition of adolescents with congenital heart disease from pediatric to adult care should be targeted to the teen’s emotional and physical developmental status, according to a scientific statement from the American Heart Association.

More children with congenital heart disease are surviving to adulthood, creating a need for programs to help them transition from pediatric to adult medical environments, said writing committee cochairs Dr. Craig Sable of Children’s National Medical Center in Washington and Dr. Elisey Foster of the University of California, San Francisco, and their colleagues wrote in “Best Practices in Managing Transition to Adulthood for Adolescents with Congenital Heart Disease: The Transition Process and Medical and Psychosocial Issues.”

An ideal transition program should “foster personal and medical independence and a greater sense of control over health, [health care] decisions, and psychosocial environment,” the committee wrote (Circulation 2011 Feb 28 [doi:10.1061/CIR.0b013e3182107c56]).

The statement recommends actively involving adolescents in the transition process, but timing the transition according to the patient’s emotional and developmental maturity. The pediatric cardiologist should initiate a transition plan, and work with the adolescent to develop the plan. Clinicians should begin to direct health discussions toward the teen rather than the parent, and should encourage teens to talk privately about their quality of life concerns, such as physical restrictions, school and peer issues, and other social relationships.

Clinicians should also recognize parents’ fears and concerns, and solicit their opinions about what quality of life issues their teen might have.

Ideally, an adolescent with CHD will have a medical home with a primary care provider who will maintain a confidential record of the patient’s medical information, the committee wrote. Once the patient is established with a cardiologist, that clinician should update the patient’s records with the primary care provider.

Surgical considerations for adolescents with CHD should include consulting an adult CHD (ACHD) expert during preoperative planning for elective surgery, choosing a clinical setting (pediatric or adult), basal on the patient’s preferences and developmental status, and enlisting an anesthesiologist familiar with the physiologic of adolescent CHD.

Additional issues to raise with adolescent CHD patients include genetic testing, sexual activity, exercise, contraception, and insurance. In all cases, discussion should be individualized based on the teen’s developmental status.

Many pediatric cardiologists continue to care for adolescents with CHD and developmental disabilities well into adulthood, but the AHA statement endorses the creation of individual transition plans to move these patients into successful adult CHD care.

The statement reviewed the following three key elements of the transition process from pediatric to adult care that apply regardless of the specific transition model:

1. Pretransition. Introduce children with CHD to the idea of managing their own health during childhood, so they can develop the necessary skills. One model for pretransition involves a nurse practitioner or physician assistant, who starts by counseling the adolescent about diet and exercise, contraception and pregnancy, high-risk behaviors, and other concerns.

2. Transition. Use a transition curriculum to educate teens about their medical history, diagnosis, and how their hearts are different. Teens in transition to adult care should learn which symptoms are cause for concern, and understand different treatment options. Also, transitioning teens need to learn how to handle health insurance and how to schedule routine care visits and follow-up visits with specialists.

3. Transfer. Transfer care when adolescent CHD patients have shown an ability to meet their own health care needs independent of their families. The AHA recommends avoiding transfer from pediatric to adult care during medical crises or complications such as pregnancy, mental illness, or noncompliance, to avoid additional psychological stress for the patient.

The recommendations were presented on behalf of the American Heart Association Congenital Heart Defects Committee of the Council on Cardiovascular Disease in the Young, Council on Cardiovascular Nursing, Council on Clinical Cardiology, and Council on Peripheral Vascular Disease.

Dr. Sable had no financial conflicts to disclose. Dr. Foster has received research funding from Boston Scientific, Guidant, and Evolve Inc.

Options for Hypoplastic Left Heart Syndrome Compared

BY SHARON WORCESTER
EXPERT ANALYSIS FROM AN INTERNATIONAL CONGENITAL HEART DISEASE SYMPOSIUM

ST. PETERSBURG, FLA. – Both the bidirectional cavopulmonary shunt and the hemi-Fontan procedure have been used in children with hypoplastic left heart syndrome. Is one better than the other? Dr. Tom Karl, deputy director of pediatric cardiac surgery at Mater Children’s Hospital in South Brisbane, Queensland, sought to answer this question at the symposium.

One potential benefit of the bidirectional cavopulmonary shunt, he said, is decreased tricuspid insufficiency as the ventricle’s geometry normalizes from volume unloading.

Other potential benefits include avoidance of later hypertrophy and subendocardial ischemic damage. General hemodynamic stability is promoted by improvement in effective systemic output – with reduced interstage mortality, better somatic growth, and the opportunity to correct associated abnormalities out of the neonatal period, he added. But is the bidirectional cavopulmonary shunt better than the hemi-Fontan procedure when it is used as the second stage in the typical three-stage treatment sequence (between neonatal palliation, e.g., Norwood procedure, and a Fontan operation) for the univentricular heart?

There are some advantages: It is technically simpler; it can be performed on a beating heart at normothermia, and off pump in many cases; and it requires no prosthetic material. It also is a good setup for an extracardiac variant of the Fontan operation.

“On the other hand, there is some potential for stenosis, and there is probably some asymmetry of flow in many cases,” said Dr. Karl.

The hemi-Fontan doesn’t have asymmetry of flow; there is actually very good flow to the left lung, he said. Also, there is a long, favorable history of this type of anastomosis specifically in hypoplastic left heart syndrome, and the hemi-Fontan provides a good setup for a lateral tunnel Fontan completion. Stenosis risk is minimal.

However, the hemi-Fontan is technically more complex. It requires cardiopulmonary bypass, which some surgeons choose to do using extracardiac circulatory arrest, and it may pose greater risk to the sinoatrial node. The hemi-Fontan also requires a considerable load of prosthetic material, but this is not seen as a disadvantage if the procedure follows a Norwood procedure, noted Dr. Karl, who said he had no conflicts of interest.

Make Move Before Hormones Kick In

So many life changes take place during the late teens and early twenties, including evolving psychosocial, economic, geographic, and educational or work factors. Preparing young people with chronic illness to transition to adult care must include an understanding of this framework in order to effectively transfer them to a system that requires self-determination. Currently, this is done in a hit-or-miss fashion. Production of guidelines, developed by a consensus process, is an essential step toward changing practice patterns and planning for the institutional resources needed to facilitate successful transfer.

Surveys of pediatricians indicate that finding time to provide adolescents with appropriate guidance for their health care issues is a significant concern. Within pediatric cardiology programs, the guidance around lifestyle and health care is often provided by allied health professionals, but these resources are stretched thin.

One of the most serious challenges facing doctors and patients is the lack of funding for case management that spans the period of transfer. Many of the problems faced by young people particularly those with chronic disease relate to financial and psychosocial issues. Although most adolescent patients have support advanced practice nursing and social services to pediatric programs, this support does not exist in the adult health care system except in the most extreme cases. Successful transfer requires not only a smooth takeoff, but also a secure landing. These resources must be developed for at least the 20-something population to ensure continued access to the appropriate health care providers.

My advice to clinicians is to start before the hormone surge. Preteens are often the most receptive. It’s helpful to begin the conversation with the patient and family as soon as possible, and to repeat it often.

ROBERTA G. WILLIAMS, M.D., is a pediatric cardiologist at Children’s Hospital in Los Angeles. She is a member of the committee that developed the statement. She reported that she had no financial disclosures.