

# Congenital Heart Disease Guidelines Target Adults

BY DIANA MAHONEY  
New England Bureau

The unique lifetime care needs of adults with congenital heart disease—particularly young adults who are making the transition out of pediatric cardiology care—are the focus of new practice guidelines released jointly by the American College of Cardiology and the American Heart Association.

The first of their kind in the United States, the adult congenital heart disease (CHD) guidelines are designed to help cardiologists make routine clinical decisions for the ever-increasing number of patients who, thanks to advances in the treatment of CHD, are now surviving into adulthood but are doing so with complex cardiac anatomy and physiology related to the repaired heart defects, according to Dr. Carole A. Warnes and her colleagues on the American College of Cardiology/American Heart Association guidelines writing committee. “In particular, there are a substantial number of young adults with single-ventricle physiology, systemic right ventricles, or complex intracardiac baffles who are now entering adult life,” the authors wrote in the executive summary of the guidelines (*J. Am. Coll. Cardiol.* 2008;52:1-121; *Circulation* 2008;118:2395-451).

The infrastructure of most pediatric cardiology centers supports the multiple unique needs of children with CHD through, for example, comprehensive case management by advanced practice nurses and social workers, but the adult health care system is not similarly structured, the authors noted. Additionally, “young adults

have many psychological, social, and financial issues that present barriers to proactive health management,” they wrote. In an effort to minimize “the compound effects of a complex and unfamiliar disease with an unprepared patient and healthcare system,” the practice guidelines outline the most important diagnostic and management strategies and indicate when to refer patients to a highly specialized center.

Improving the delivery of care and ensuring access to care figure prominently in the recommendations. The guidelines include these recommendations:

- ▶ Care of adult CHD patients should be coordinated by regional centers of excellence.
- ▶ Adult CHD patients should carry a complete “medical passport” containing their medical histories and contact information for the regional centers of excellence.
- ▶ Designated health care guardians should be included in the medical decision-making process for patients whose care is complicated by additional special needs.
- ▶ Patients should have a primary care physician and a local cardiovascular specialist, each of whom has copies of current clinical records on file.
- ▶ Patients should establish a relationship with a regional adult CHD center to ensure the availability of care when needed.

The guidelines specify that, in the absence of specific training or experience in adult CHD, primary caregivers and cardi-

ologists of patients with CHD should work in collaboration with trained specialists, and patients should have access to specialized follow-up care. For example, the guidelines state that patients with low-risk, simple CHD should have at least one follow-up at a regional adult CHD center, while more frequent follow-up (every 12-24 months) is advised for “adults with complex and moderate CHD.”

**An increasing number of patients are now surviving into adulthood with complex cardiac anatomy and physiology.**

DR. WARNES

urgently or acute care in most cases, the performance of diagnostic or interventional procedures, surgical procedures requiring general anesthesia or conscious sedation, urgent or acute care of cardiac problems, and urgent or acute care of noncardiac problems in high-risk patients.

The guidelines also address the psychosocial needs of adult CHD patients with the recommendation that the comprehensive care of these patients should incorporate individual and family psychosocial screening, counseling, and education regarding the possible social, emotional, and vocational impact of CHD.

Because CHD patients are at increased risk for infectious endocarditis, it is important that patients and their families be educated about the signs and symptoms of infectious complications, as well as how to

prevent them, according to the authors. Specifically, the guidelines recommend antibiotic prophylaxis in high-risk CHD patients “before dental procedures that involved manipulation of the gingival tissue or the periapical region of teeth or perforation of the oral mucosa.” However, antibiotic prophylaxis against infectious endocarditis “is not recommended for nondental procedures [such as esophagogastroduodenoscopy or colonoscopy] in the absence of active infection,” the guidelines state.

Pregnancy and contraception require special consideration in women with CHD. With respect to contraception, oral estrogen-containing drugs are not recommended for patients at risk of thromboembolism, including those with pulmonary arterial hypertension or cyanosis related to an intracardiac shunt, according to the guidelines. Patients are advised to consult with an adult CHD expert to determine a labor and delivery management plan prior to becoming pregnant.

In addition to the general recommendations for the care of adult CHD patients, the guidelines also include comprehensive information on the clinical features, diagnosis, treatment, and preventive strategies related to specific lesions.

Although the guideline recommendations are evidence based wherever possible, “unlike other ACC/AHA practice guidelines, there is not a large body of peer-reviewed published evidence to support most recommendations,” the authors wrote. For this reason, the evidence supporting many of the recommendations comes from the consensus of experts. ■



## Exercise Is Safe, Beneficial in Patients With Heart Failure

BY CAROLINE HELWICK  
Contributing Writer

NEW ORLEANS — In the largest study of exercise training as part of the management of heart failure to date, a guided exercise program was safe and modestly effective, but researchers acknowledged that patients found it hard to keep up the routine.

The safety of exercise training in heart failure patients, outside of a supervised environment, has been a concern. This study proved benefits could be obtained without excess risk, said Dr. Christopher M. O'Connor, presenting results of the Heart Failure and A Controlled Trial Investigating Outcomes of Exercise Training (HF-ACTION) study at the annual scientific sessions of the American Heart Association.

“Over 30 randomized trials have shown increased exercise capacity and possibly improved survival with exercise training, but these were largely single-center studies that were underpowered or lacked adequate controls and produced limited data on safety,”

he noted at a press conference.

HF-ACTION, a randomized, phase III trial sponsored by the National Heart, Lung, and Blood Institute, followed 2,331 heart failure patients at 82 international sites for an average of 2.5 years. The relatively young population, median age 59 years, had an average left ventricular ejection fraction (LVEF) of 25%, indicating moderate HF. History of coronary occlusion and prior myocardial infarction was common.

Patients were randomized to an exercise training program aimed at increasing workout intensity and duration or to usual care, where they were encouraged to exercise, based on the American College of Cardiology/AHA recommendations of 30 minutes of moderate exercise most days of the week. Both groups received optimized medical treatment, patient education, and follow-up telephone calls.

The exercise training followed the cardiac rehabilitation model. Patients were prescribed a multi-stage, guided workout of 36 supervised training sessions of 30

minutes of exercise three times a week. At the 18th session, patients received a treadmill or exercise bicycle for home use, learned how to monitor their heart rate during exercise, and were encouraged to complete five weekly sessions of similar intensity and 40 minutes' duration.

At 4-6 weeks, patients were exercising a median of 95 minutes per week, short of the goal of 120 minutes. This was consistent for the first year and then diminished further.

After 3 years, people were exercising for about 50 minutes. We had wanted them to exercise for 120 minutes. So adherence is extremely difficult,” reported Dr. O'Connor, professor of medicine and director of the heart center at Duke University Medical Center, Durham, N.C.

Exercise training was not associated with a significant reduction in the primary end point, all-cause mortality and hospitalization, or in secondary composite end points: cardiovascular (CV) mortality plus CV, and CV mortality plus HF, he reported.

But improvements in outcomes emerged in the prespecified adjusted analysis that accounted for additional key prognostic variables related to heart failure outcomes. These included exercise duration, LVEF, Beck Depression Inventory score, and history of atrial fibrillation/flutter.

In the adjusted analysis, the primary end point was significantly reduced by 11%, and CV mortality plus heart failure hospitalization was significantly reduced by 15%. The reduction in CV mortality plus CV hospitalization remained a nonsignificant 8%.

“The prespecified adjusted analysis is a fair analysis of these data and is probably closest to the truth,” Dr. O'Connor maintained. “Prognostic factors are most important.”

The study found no excess risk for CV events or fractures with intensive exercise. “Perhaps the most important finding is that exercise training of this degree was safe,” Dr. O'Connor added.

Health status was assessed by the Kansas City Cardiomyopathy Questionnaire (KCCQ). In

the exercise group, the average KCCQ score rose by 5 points after the first 3 months of training, a statistically and clinically significant increase that continued for the remainder of the study. In the usual-care group, the average KCCQ score rose by 3 points, which was also maintained. The 3-point increase was statistically significant but fell short of clinical significance. The increase in the usual-care group was significantly less than in the exercise group, reported Kathryn E. Flynn, Ph.D., of the Center for Clinical and Genetic Economics at Duke University, Durham, N.C.

The improvements in outcomes were obtained in a setting of excellent overall cardiac care, as more than 90% of the patients received evidence-based medical therapy for their disease. “We achieved an 11% to 15% meaningful reduction in clinical end points above that, with a safe intervention,” Dr. O'Connor emphasized. ■

Philadelphia bureau chief Mitchell L. Zoler contributed to this report.