INTRODUCTION

The expansion of the population of adults with congenital heart disease (CHD) and the increasing survival of patients with complex disease into adulthood have heightened the need for specifically trained individuals who can provide comprehensive outpatient and in-patient care and consultative services to these patients (1–3). In addition, such individuals should have the educational background necessary for successful academic careers in order to advance knowledge and educate other providers. At present, only a few specialists in the U.S. have been specifically trained for this role. Most adult congenital heart disease (ACHD) patients are followed by adult cardiologists who have not had much training in the diagnosis or management of CHD or by pediatric cardiologists who have had little or no experience or training in comprehensive adult care. Adult cardiologists often unofficially consult with pediatric cardiologists to plan management, but uncompensated time and medico-legal risks have made this practice increasingly difficult for pediatric cardiologists. Pediatric cardiologists may effectively co-manage adult patients with an internist or family medicine practitioner, but they cannot provide the full complement of in-patient or invasive services that may be needed. In some cases, adult and pediatric cardiologists follow ACHD patients in a joint clinic. These practices vary considerably depending on patient volume, institutional resources, and physician interest.

The routes by which adult and pediatric cardiologists in this field arrived at their level of expertise are varied. Many, if not most, adult cardiologists have had on-the-job training which provided them with an opportunity to learn, in an environment of collaboration, from pediatric cardiologists and cardiac surgeons. Many pediatric cardiologists have become increasingly involved with adults with CHD as their pediatric patients have aged. Although ACHD patients will continue to rely on these traditionally trained...
cardiologists for their care, a specifically trained workforce is called for, as described here.

The aim of this section is to describe the educational requirements for the creation of the specialized cardiology workforce that would be best qualified to fill the roles of caregiver for ACHD patients, team leader of regional programs, and academic leader who will advance the field. The workforce required to successfully care for this population also includes personnel such as experienced mid-level providers (e.g., advanced practice nurses and physician assistants), psychologists, social workers, and obstetricians, but their workforce requirements and educational needs are beyond the scope of this document.

**LEVELS OF TRAINING IN ACHD**

Because some basic training in CHD is necessary for all adult cardiology trainees in the U.S., a system must be devised that enables adult cardiology training programs to offer educational experience in CHD. At a minimum, this allows the trainee to recognize CHD and attempt to make a preliminary diagnosis, to refer the patient to a regional ACHD center, and to work with that center in the care of these patients.

The terminology used in this document for ascending levels of training (Levels 1, 2, and 3, with Level 3 being the highest) is derived from definitions adopted from the Core Cardiology Training Symposium 2 (COCATS II) (4), which recommends training requirements for adult cardiovascular specialists: Level 1—requires basic training of all adult (medical) cardiology trainees so they may become competent consulting cardiologists; Level 2—requires additional training in a specialized area to enable the cardiologist to perform or interpret, or both, specific procedures or skills at an intermediate skill level; and Level 3—requires additional training in a specialized area to enable the cardiologist to perform, interpret, and train others to perform and interpret specific procedures or acquire skills and knowledge at a high level.

Level 1 training consists of basic exposure to CHD patients and organized educational material on CHD. To enable proper recognition of the problems of adults with CHD, and to be cognizant of when specialized referral is needed, all medical cardiology fellows must achieve Level 1 training in CHD. Level 1 trainees should be instructed by a faculty member with Level 2 or 3 training, or its equivalent. A pediatric cardiologist should also be involved in these training exercises. Level 1 training can be achieved, in part, by core curriculum lectures, assigned reading or audiovisual aids (e.g., videotapes), and case management conferences. Core, or Level 1, training should include didactic material on CHD anatomy, physiology, pathology, genetics, natural history, clinical presentation, and management. Case management conferences should include a review of data on, and medical images of, ACHD patients. During training in electrocardiography, echocardiography, nuclear cardiology, and cardiac catheterization, trainees should be exposed to the evaluation of CHD with these modalities. Postoperative sequelae and residual abnormalities should be stressed, as well as appropriate follow-up protocols and indications for intervention.

Adult cardiology trainees planning to care for ACHD patients (Level 2 training) should have, in addition to the didactic material recommended earlier, at least one year of training in ACHD. This should be an intensive program with exposure to all the components of Level 3 training, but in lesser amounts. Level 3 trainees need at least two years of training.

**COMPETENCIES REQUIRED FOR LEVEL 2 AND LEVEL 3 SPECIALISTS**

The specific competencies required of Level 3 ACHD leaders and trainers will aid in defining the structure of the training program these individuals will require. They are as follows:

1. Medical and surgical management of CHD.
2. Postoperative management of adults with CHD.
3. Technical and diagnostic expertise in invasive and noninvasive cardiac procedures.
4. Recognition and management of acquired cardiovascular and cardiopulmonary disease.
5. Physiologic changes of pregnancy and awareness of the important effects on and presentation of CHD.
6. Recognition and appropriate initial management of noncardiac disease in adults.
7. Direct and meaningful experience with clinical research methodology, including fundamentals of clinical epidemiology.
8. Embryology, morphology, and pathophysiology of CHD.
10. Psychosocial aspects of adolescence and the transition to adulthood.
12. Life-style counseling and advocacy for adolescents and adults with CHD.

The cardiologist specializing in ACHD in the U.S. will usually not be fully employed in the care of only ACHD patients and will remain in active practice in either pediatric or adult cardiology. At present, if an adult medical cardiology trainee plans to combine the practice of pediatric and adult CHD, sufficient general pediatric and pediatric cardiology training would be required to attain certification in pediatric cardiology. If a pediatric cardiology trainee wishes to combine the practice of pediatric and adult CHD, sufficient medical cardiology training would be required to qualify him or her for certification in adult cardiovascular medicine.
**LEVEL 2 AND LEVEL 3 TRAINING PATHWAYS**

The means by which a trainee may arrive at advanced training are currently diverse. No set pattern has been formally recognized for training in this area, but delineation of desirable pathways is appropriate. The time required for the training of future ACHD cardiologists in pediatrics, adolescent medicine, internal medicine, adult and pediatric cardiology, and research methodology should be determined by a special task force of the American Board of Internal Medicine (ABIM) and the American Board of Pediatrics (ABP), facilitated by the American College of Cardiology (ACC). It is strongly recommended that these boards develop some flexibility in the amount of adult combined with pediatric experience required for eligibility for examinations in the future, because of the inordinately long periods currently required for the full complement of training in both fields. There is also the possibility of incorporating the unique Medicine/Pediatrics training program as a pathway to subspecialization in this field.

For Level 2 and 3 trainees, the standards of knowledge and proficiency in echocardiography must include detailed knowledge of all aspects of standard transthoracic echocardiography (TTE) and transesophageal echocardiography (TEE) in adults with CHD, in addition to the minimal Level 3 standards for acquired adult heart disease. Echocardiographic training in CHD is usually done best in a pediatric echocardiographic laboratory. Level 3 should be characterized by the ability to independently perform and interpret TTE and TEE studies in a wide range of CHD cases. A minimum of 150 complete TTE and 25 TEE (≥10 intraoperatively) studies of patients with CHD should be performed and interpreted, with participation in the interpretation of at least 300 TTE and 50 TEE studies (20 intraoperatively). The director of the laboratory must make an assessment of each Level 3 trainee’s progress and qualifications and thus adapt the number of required studies to the individual. Even for Level 3 cardiology trainees, it is recognized that some aspects of echocardiography (e.g., fetal studies) will not likely fall within their practice skills, and some studies should be referred to a pediatric echocardiographer. Nonetheless, awareness of the role of and implications of fetal echocardiographic data in the management of their ACHD patients is essential.

All cardiology fellows are required to have a defined minimal exposure to cardiac catheterization, including basic knowledge of the various procedures, indications and complications of these procedures, and a specified amount of hands-on training. Level 2 and 3 trainees should also have basic knowledge of the angiographic anatomy of a wide variety of CHD cases, as well as an understanding of the pertinent hemodynamic data. Regular attendance at weekly case management conferences and review of preoperative data, including catheterization and medical imaging data, comprise the first step toward acquiring this familiarity. Direct hands-on catheterization experience in a variety of CHD cases should be required: at least 20 patients for Level 2 and at least 40 patients for Level 3 training in ACHD, over and above core cardiology training (pediatric or adult).

Individuals seeking training in advanced or interventional catheter therapy of ACHD patients will require at least one additional year of specialized training at a tertiary care center with large patient volumes and abundant staff expertise. In addition to the need for direct participation in many more diagnostic catheterizations in patients with CHD (minimum of 100 cases) than the minimums described earlier, training should include sufficient exposure to all techniques of CHD interventional therapy, including balloon dilation, vascular stenting, and coil or other device insertion, so that the cardiologist can ultimately be qualified as an independent operator.

Electrophysiology services are vital in managing adults with CHD, particularly in the postoperative group. An electrophysiologist with expertise in ACHD should be involved in the care of any of these patients with recurrent or problematic arrhythmias. Whether such a person is primarily trained in pediatric or adult electrophysiology is not important; however, they should have some training in both pediatric and adult electrophysiology environments.

It is expected that physicians who will be primarily responsible for the management of arrhythmias in ACHD patients will have: 1) Board certification in cardiac electrophysiology (ABIM- or ABP-sponsored Added Qualification Examination); and 2) completed a fellowship training program in adult or pediatric electrophysiology in accordance with North American Society for Pacing and Electrophysiology (NASPE) guidelines (minimum of two years duration). Such individuals will have attained the prerequisite experience in arrhythmia management, pacemaker and automatic implantable cardioverter defibrillator devices, electrophysiology, and intracardiac mapping.

The electrophysiologist caring for adults with CHD must have a sound knowledge of the underlying anatomy and surgical approaches. It would be preferable for such an individual to spend three to six months in a congenital cardiac program (both pediatric and adult) involved in the clinical care of these patients. Such a program should include exposure to the commonly performed surgical procedures. The electrophysiology fellowship program should include a minimum of six months of training specifically in intracardiac mapping and ablation in a recognized center that has substantial expertise in the ablation of complex atrial and ventricular arrhythmias. This would include training in the use of currently available electroanatomic mapping systems. As intra-atrial arrhythmias (as a consequence of underlying pathophysiology and/or previous surgical procedures) are often complex in nature in these patients, and as they are an important contributor to morbidity and possibly to mortality, such training would be essential for the individual wishing to perform catheter ablation in these patients.
Level 2 and 3 trainees should be exposed to other specialists working in this area, including cardiac anesthetists, intensivists, other medical subspecialists, mid-level providers, and other professionals, such as psychologists and physical therapists. Level 3 trainees must participate in basic science or clinical research that relates to CHD.

A skilled and versatile cardiovascular surgeon is key in the tertiary care center. A surgeon must have extensive experience in congenital and acquired cardiovascular disorders before acquiring supervised experience in the surgery of ACHD patients. Level 2 and 3 trainees should learn much about the surgical issues that arise in the care of these patients and should be familiar with postoperative problems of common operations, such as repaired tetralogy, atrioventricular septal defect, conduits, and Fontan repair.

Level 2 and 3 trainees should also have a solid understanding of the potential impact of co-morbidities on the patient’s management and course; knowledge of the problems of pregnancy in relation to cardiac anomalies and of the effects of drugs on the mother and fetus; and information on contraception, transplantation, exercise, employment, life insurance, and the operation of motor vehicles and airplanes. They should attend regular didactic rounds and case management conferences.

**MID-LEVEL PROVIDERS**

This term is used to include advanced practice nurses and physician assistants. For mid-level providers and others practicing in an ACHD setting, special training and work experience should usually be built on a strong clinical base in medical or pediatric cardiology. Depending on the needs of the ACHD center, the advanced practice nurse or physician assistant can be specially trained to assist with cardiac catheterizations or to perform echocardiography and other cardio-diagnostic studies. Experience in managing critically ill adults is important, and such personnel may benefit from a background in a coronary care or intensive care unit. Excellent communication skills are imperative. An advanced practice nurse (clinical nurse specialist or nurse practitioner) holds a Master’s degree in nursing, with subspecialization in areas such as cardiology, pediatrics, or “acute care.” State certification is offered upon graduation from an accredited school. National certification is granted after passing a Board examination. Prescriptive privileges vary from state to state. Physician assistants are certified to practice under their supervising physician’s license after a two-year program that prepares them for responsibilities similar to those of advanced practice nurses. Admission to a physician assistant program in the U.S. usually demands a Bachelor’s degree, with specific science requirements.

**FACILITIES FOR TRAINING IN ADULT CHD**

It is likely that Level 2 and 3 training in ACHD will remain the task of tertiary care regional centers over the next decade. A variety of clinical laboratories must provide the trainee with ample exposure to the various techniques employed in caring for adults with CHD: cardiac catheterization, electrophysiology and pacemakers, electrocardiography, exercise and pharmacologic stress testing, Doppler echocardiography, ambulatory electrocardiographic monitoring, nuclear cardiology, magnetic resonance imaging and computed tomography, peripheral vascular testing, pulmonary function, and pathology. In addition, there must be fully equipped cardiac and intensive care units, as well as cardiac and vascular surgery sections. A comprehensive medical library and continuing professional development programs must also be available.

The ACHD team should care for adults with CHD admitted to an in-patient service. To provide a wide range of experience, Level 2 and 3 trainees should participate in the evaluation and management of all adults with CHD admitted to the hospital. In-patient admissions may be for elective or emergency admissions for general medical diseases or conditions related to their malformation (e.g., hemoptysis, endocarditis). Admissions may also be for labor and delivery, diagnostic or interventional catheter procedures, electrophysiologic ablation, or noncardiac surgery. For patients who are admitted directly to the care of a congenital cardiovascular surgeon, a Level 2 or 3 trainee should aid the consulting ACHD cardiologist before and after the operation, as well as provide or arrange any cardiology intraoperative services (e.g., intraoperative trans-esophageal echocardiography).

**RESEARCH AND INTELLECTUAL ENVIRONMENT**

A culture of research (from cell to community) needs to be emphasized in ACHD training centers. Clinical research data should be shared through collaborative studies with other centers and peer-reviewed published data should be exchanged with other centers to provide ever-improving care for this group of patients and to enhance the intellectual environment for trainees and faculty. Because each type of complex congenital cardiac disease is relatively rare, necessary information from several tertiary care regional centers should be prospectively pooled to develop clinical studies with sufficient power to answer the research questions, particularly those examining interventions and outcomes.

The creation of specific ACHD research fellowships is recommended. This would permit individuals to dedicate 75% to 100% of their time to research, over a guaranteed two- to three-year period, any aspect of ACHD (biomedical, clinical, health services, or population research). Such fellowships would help build a cadre of enhanced research personnel in ACHD. It is further recommended that a specific network of centers of excellence in care for adults with CHD be created and funded through the National Heart, Lung, and Blood Institute.
CONCLUSIONS

At present, the physician workforce caring for ACHD patients in the U.S. consists of a few (<20) adult cardiologists with advanced training, as described, and an ongoing career focus in ACHD, as well as a much larger number of adult and pediatric cardiologists with little or no specific training in the care of ACHD patients, but with on-the-job experience. Development of a small but highly trained cohort of ACHD specialists who could lead an integrated network of specialized centers would improve clinical care, advance knowledge, and help provide ongoing professional education for the larger population of adult and pediatric cardiologists who care for the majority of these patients.

Creating this population of ACHD specialists requires the clear articulation of training pathways and certification. Because of the long time required for training in CHD and adult diseases and research, some consolidation of training will be needed, in addition to the development of specific training funds and the establishment of debt relief to attract and maintain an adequate workforce.

RECOMMENDATIONS

- A joint task force of the ABIM and ABP, facilitated by the ACC, should be formed to determine the specific pathways and years of training required for Level 2 and 3 ACHD subspecialist cardiologists.
- Level 2 and 3 training programs should be coordinated to ensure the greatest learning opportunities for the ACHD cardiologists-in-training and to provide continuing education for trainees, graduates, and ACHD practitioners.
- ACHD research fellowships should be created so that individuals can spend 75% to 100% of their time in protected research over a two- to three-year period.
- Training programs for other key staff (e.g., nurses, physician assistants, psychologists, social workers, other non-physician personnel) on ACHD teams should be established.

Task Force 4: Organization of Delivery Systems for Adults With Congenital Heart Disease

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ORGANIZATION OF DELIVERY SYSTEMS FOR ACHD

The delivery of appropriate care to adults with congenital heart disease (ACHD) is a largely unmet challenge in the U.S. and elsewhere. To meet this challenge, a structure and process for the organization and delivery of care is proposed. We will use the “severe heart failure care model” familiar to most cardiologists as an example of how the needs of ACHD patients can best be met. Similar to the challenge of the severe heart failure patients, ACHD patients have a low-to-moderate prevalence, need caregivers with both special knowledge of the conditions encompassed and the ability to provide tailored and out-of-the-ordinary treatments, and may require high-intensity medical care. By contrast to the heart failure population, ACHD patients reach age 18 at a rate of about 9,000 annually in the U.S. and may require much longer surveillance and care than most heart failure patients.

In this section we will: 1) describe the “severe heart failure model” that we propose should be emulated for ACHD patients, 2) describe the structure of such a program based on the concept of regional ACHD centers across the U.S., 3) outline the resources (services and personnel) required in such centers, 4) propose responsibilities for different types of physicians in the care of these patients, 5) describe the initial patient visit and its goals, 6) propose strategies for long-term follow-up, and 7) make some comments regarding hospitalization of these patients.

SEVERE HEART FAILURE AS A MODEL OF REGIONALIZATION AND CENTRALIZATION

The established “local caregiver or center supported by a regional specialized center” model for the organization and delivery of care for adult patients with severe heart failure serves as a paradigm for our proposal for a system of care for ACHD. When compared with the average cardiology patient, those with severe heart failure tend to carry high