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 3 REFERENCE LIST


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

Michael J. Landzberg, MD, FACC, Co-Chair, Daniel J. Murphy, Jr, MD, FACC, Co-Chair, William R. Davidson, Jr, MD, FACC, John A. Jarcho, MD, FACC, Harlan M. Krumholz, MD, FACC, John E. Mayer, Jr, MD, FACC, Roger B. B. Mee, MD, ChB, David J. Sahn, MD, FACC, George F. Van Hare, MD, FACC, Gary D. Webb, MD, FACC, Roberta G. Williams, MD, FACC

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
levels of medical complexity and incidence of recurrent illness, and they have less-optimal outcomes.

Given the supposition by internists and cardiologists that a great deal of heart failure management falls within their own expertise, patient care, including that for the most severely ill, previously tended to be spread throughout all levels of adult cardiovascular care. This model tended to limit the capacity to expand services, apply new knowledge, share experiences, and compare outcomes. The organization of best practice guidelines was difficult, and translation of such recommendations to everyday care was limited. Improvement in average care was gradual.

Because of a growing accountability to third-party payers and limited organ donor procurement, a new model for organizing and delivering care to the most severely ill arose, centered around a specialized regional program and working in conjunction with local providers of care. This system has evolved over a 20-year period, fulfilling most expectations for the provision of high-quality care. The severe heart failure model has allowed for: 1) improved teaching, collection, and dissemination of knowledge regarding heart failure and its ramifications; 2) new treatments, many of which could not be tested without sufficient numbers of patients and resources; 3) decreased outpatient visits, fewer hospitalizations, and improved patient quality of life; 4) improved medical and surgical outcomes; 5) containment of costs; 6) a more uniform pattern of medical care (allowing improved cooperation and cross-referral of patients and better definition of the appropriateness of medical and surgical care at a local, compared with a regional, center); and 7) a greater interaction between third-party payers, insurers, and medical caregivers.

This model has required the growth and development of both a national registry and regional databases to collect, organize, interpret, and distribute standardized and requested information and to review this in a timely fashion. Individual institutions maintain financial commitments to the maintenance of the databases and to the employment of medically savvy data collection and entry personnel. All institutions have access to their individual data and have the opportunity to initiate issue-driven research. Evidence-based recommendations can be generated with actual data and analysis requested by and determined in large part by the medical caregivers themselves.

The local and regional model of medical care functions well for this relatively small group of patients in need of expert and evidence-based care. A similar system will allow caregivers for ACHD to achieve the same rewards already obtained for adults with severe heart failure.

EVALUATION OF QUALITY

Health care quality has been classified into three components: structure (training and skills of personnel, adequacy of diagnostic and therapeutic equipment resources, and organizational systems that mobilize these resources most efficiently for optimal patient care), process (the use of appropriate diagnostic and therapeutic modalities for individual patients), and outcomes (the consequences of treatment).

PROPOSED STRUCTURE OF THE HEALTH CARE DELIVERY SYSTEM FOR ADULTS WITH CONGENITAL HEART DISEASE

An algorithm for the initial evaluation and ongoing care of ACHD is proposed. These recommendations include the subdivision and coordination of care of ACHD both locally and at regional ACHD centers. This model requires a system of data storage, rapid communication, critical self-analysis, establishment and implementation of practice guidelines, and insights to provide for the coordination of optimal current and future care of ACHD.

LOCAL (INDIVIDUAL PHYSICIAN AND CARDIOLOGIST)

Local medical resources for ACHD may be a family doctor, an internist, or a general cardiologist on the one hand, and an ACHD cardiologist with a commitment to, training in, and/or experience with the care of ACHD on the other. The first three groups of physicians will usually have a major or exclusive role in the types of patients listed in Table 6 of Task Force #1. These local clinicians might also participate in the care of adults with moderate and complex CHD (Tables 4 and 5 of Task Force #1) in collaboration with the staff of a regional ACHD center.

The ACHD cardiologists (who also practice as pediatric or adult medical cardiologists) can care for any ACHD patient. At present, the majority of ACHD cardiologists will have had informal training and on-the-job experience in the care of ACHD (see Task Force #3). More recently, a few training centers have produced ACHD cardiologists with comprehensive training and often a commitment to contribute academically to the ACHD discipline.

THE REGIONAL ACHD CENTER

A regional ACHD center is usually directed by an ACHD cardiologist who is supported by a collaborative, multidisciplinary team involving other cardiologists, mid-level practitioners, congenital heart surgeons, and others. The specific components of such a program are outlined in Table 1. Regional ACHD centers will frequently serve as the entry point for ACHD. They may receive patients from sources such as general pediatric and adult medical cardiologists, other specialists (e.g., obstetricians), primary care providers, patient self-referrals, and medical insurers. Every ACHD patient should be evaluated at least once by an ACHD cardiologist for the purpose of initial evaluation and recommendations for long-term care. Ideally, this applies even to the patients in Table 6 of Task Force #1, so-called simple CHD. This is particularly true for patients who have not been under the care of pediatric cardiologists. The goal of
the visit is to ensure that other diagnoses or subtle but important findings have not been missed. Too often, patients with “simple” CHD are seen who have been misdiagnosed, mismanaged, or misinformed. Caregiver and insurance referral patterns will often require reconfiguration for referral to caregivers with specific expertise in ACHD care.

Regional ACHD centers may be established within an adult hospital, a children’s hospital, a unit shared by both children and adult hospital facilities, or a freestanding unit. Such centers must afford prompt access for patients and referring physicians in order to provide:

**Comprehensive diagnosis**—All modes of cardiac diagnosis should be available. Each component of the diagnostic evaluation should be performed by individuals with appropriate training and experience in CHD.

**Management planning**—Best decisions have traditionally occurred within the venue of a case-management conference, at which personnel from cardiology, cardiac surgery, anesthesia, intensive care, and nursing review relevant data. Case-management conferences with discussion and consensus are very important in determining care strategy (including both the nature and timing of intervention) as well as educating and building the cohesion of team members.

**Patient counseling**—Within a regional ACHD center adults with CHD should participate in an informed discussion of their current medical/cardiac situation and their proposed management plan.

Specific personnel and services within regional ACHD centers are also necessary, including:

**Cardiac anesthesia**—The presence of a cardiac anesthesia team that offers consultative services, interacts with other members of the ACHD caregiving team, and anesthetizes patients with CHD is required.

**Operating rooms**—Operating facilities with prompt or immediate access to all perioperative (e.g., echocardiography, catheterization) and intraoperative (e.g., transesophageal echocardiography) diagnostic procedures are essential. Dedicated fully trained congenital cardiac perfusionists (with expertise in VAD and ECMO setup, delivery, and maintenance) are mandatory.

**Cardiac surgery**—In addition to adult cardiovascular surgeons, regional ACHD centers require the availability of full-time, expert congenital heart surgeons. At least two congenital heart surgeons (often based primarily at a children’s hospital) are required to provide 24-h coverage for both the pediatric and adult facilities. Their surgical teams should be expected to maintain their expertise through performing a critical annual volume of pediatric and ACHD surgeries.

---

### Table 1. Personnel and Services Recommended or Required for Regional ACHD Centers

<table>
<thead>
<tr>
<th>Type of Service or Personnel</th>
<th>Local Care</th>
<th>Regional ACHD Center</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric ACHD cardiologist</td>
<td>Optional</td>
<td>One or several 24/7*</td>
</tr>
<tr>
<td>Adult medical ACHD cardiologist</td>
<td>Optional</td>
<td>One or several 24/7*</td>
</tr>
<tr>
<td>Mid-level practitioner</td>
<td>Optional</td>
<td>Two/several</td>
</tr>
<tr>
<td>Congenital heart surgeon</td>
<td>No</td>
<td>Two/several 24/7*</td>
</tr>
<tr>
<td>Cardiac anesthesia</td>
<td>No</td>
<td>Several 24/7*</td>
</tr>
<tr>
<td>Echocardiography</td>
<td>Refer to regional ACHD center</td>
<td>Two/several 24/7*</td>
</tr>
<tr>
<td>Includes TEE, intraoperative TEE (required for surgery)</td>
<td>Refer to regional ACHD center</td>
<td>Yes 24/7*</td>
</tr>
<tr>
<td>Diagnostic catheterization**</td>
<td>Refer to regional ACHD center</td>
<td>Yes 24/7*</td>
</tr>
<tr>
<td>Noncoronary interventional catheterization**</td>
<td>Refer to regional ACHD center</td>
<td>Yes 24/7*</td>
</tr>
<tr>
<td>Electrophysiology**</td>
<td>Consult regional ACHD center unless unrelated to CHD</td>
<td>Yes 24/7*</td>
</tr>
<tr>
<td>Exercise testing</td>
<td>Standard</td>
<td>Echo, radionuclide, cardiopulmonary, metabolic heart, lung, heart-lung desirable</td>
</tr>
<tr>
<td>Transplant</td>
<td>Optional</td>
<td>CT scan, cardiac MRI with fast-pulse sequencing*, nuclear medicine</td>
</tr>
<tr>
<td>Cardiac imaging/radiology services</td>
<td>Optional</td>
<td>Yes</td>
</tr>
<tr>
<td>Cardiac pathology</td>
<td>Optional</td>
<td>Data collection</td>
</tr>
<tr>
<td>Information technology</td>
<td>Optional</td>
<td>Database support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interface with local practitioners, including internet-based applications</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Quality assessment review and protocols</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Optional development of best practice guidelines</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>Adolescent transitional unit</td>
</tr>
<tr>
<td></td>
<td></td>
<td>High risk obstetrics</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Genetics</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rehabilitation services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Vocational services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Financial counselors</td>
</tr>
</tbody>
</table>

*“24/7” denotes availability 24 hours/day, 7 days/week. **These modalities must be supervised/Performed and interpreted by physicians with specific skills and knowledge in CHD, as outlined.
Intensive Care—ICU staff trained and expert in provision of care to ACHD are required in regional ACHD centers. The ICU should be sited with rapid access to the ORs and be capable of performing open-chest resuscitation and of implementing and monitoring ECMO and VAD. The ICU staff and residents/fellows can be culled from medical cardiology, cardiac anesthesia, cardiac surgery, and critical care specialties, and they should be supported by fellowship programs. Expert medical and surgical care should be on-site 24 h/day, 7 days/week. The skill of the staff in diagnosing and managing acquired cardiovascular and other diseases is very important here as well as throughout all units and services caring for ACHD patients. Timely access to all diagnostic services and interventions should be available 24 h/day. The ICU nursing staff should have specific expertise in the care and management of ACHD.

In-patient service—ACHD patients require a hospital environment with specifically qualified nursing staff and support personnel. This may be provided within the context of other medical or cardiology unit or on a unit dedicated to ACHD patient care. The unit should contain a high-intensity central nursing area with hemodynamic/electrocardiographic telemetry monitoring. Expert medical and surgical physician care should be either on-site or available in a near-immediate fashion 24 h/day, 7 days/week. Optimally, the in-hospital beds, ICU, cath lab, and ORs should be geographically clustered, in close proximity to noninvasive laboratories, outpatient areas, and cardiology/cardiac surgery administrative services. The center should support social workers and financial counselors, and it should make appropriate use of chaplaincy support.

Transplantation—Regional ACHD centers should be affiliated with a transplant program.

Electrophysiology service—A fully equipped and properly staffed service with a full range of ablative and pacing therapies, in addition to the consultative and diagnostic services appropriate to the special needs of ACHD patients, must be available.

Table 2. Types of Patients Needing Cardiac Catheterization in Regional ACHD Centers

<table>
<thead>
<tr>
<th>Procedure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Venous pathway dilation or stent placement</td>
</tr>
<tr>
<td>PDA closure</td>
</tr>
<tr>
<td>Venous pathway dilation or stent placement</td>
</tr>
<tr>
<td>Septal defect closure</td>
</tr>
<tr>
<td>Vasodilator or vascular shunt/access occlusion</td>
</tr>
<tr>
<td>&amp;/or stent placement</td>
</tr>
<tr>
<td>Septal defect closure</td>
</tr>
<tr>
<td>Aortic coarctation/RV outflow/peripheral pulmo-</td>
</tr>
<tr>
<td>Venous pathway dilation or stent placement</td>
</tr>
<tr>
<td>Gonital valve dilation</td>
</tr>
<tr>
<td>Aortic coarctation/RV outflow/peripheral pulmo-</td>
</tr>
<tr>
<td>Chronic valve dilation</td>
</tr>
<tr>
<td>Aortic coarctation/RV outflow/peripheral pulmo-</td>
</tr>
<tr>
<td>Chronic valve dilation</td>
</tr>
<tr>
<td>Aortic coarctation/RV outflow/peripheral pulmo-</td>
</tr>
</tbody>
</table>

High-risk obstetrics—24 h/day, 7 day/week coverage by staff expert in the counsel and care of women with CHD is a special requirement.

Cardiac pathology—Expertise in congenital cardiology and post-mortem examination must be available within the regional ACHD centers.

**GEOGRAPHIC DISTRIBUTION OF REGIONAL ACHD CENTERS**

The proposed regionalization described in this report should provide appropriate and continuous access, when needed, to all types of care for all ACHD in the U.S. Because geographic regions of the U.S. vary in population density and available medical resources, some flexibility in applying the principles of regionalization is appropriate. As a rule, there should be approximately one regional ACHD center per population of 5 to 10 million people and approximately 30 to 50 regional ACHD centers nationwide. In some areas of the country, regional ACHD centers may be farther apart and may have somewhat smaller ACHD populations. In the largest urban centers with several pediatric cardiology and congenital heart surgical programs there are likely to be two or more regional ACHD centers. In all regions, reciprocal communication between regional ACHD centers, local caregivers, and patients is required. In recognition of the fact that particular areas of expertise may not be equally present in each regional ACHD center, specific geographic referral patterns may overlap different regions.

**PROPOSED PROCESS FOR DELIVERY OF HEALTH CARE TO ACHD PATIENTS**

Newly arrived ACHD patients. As described in the report of Task Force #2, an orderly transition of care from the pediatric to the adult facility is most strongly recommended. One of the many reasons for this is to reduce the number of patients lost to follow-up during adolescence and young adult life. The pediatric cardiologist should provide a copy of all relevant clinical records, including operative reports, catheterization reports, and the like, to the patients and the regional ACHD centers at the time of transfer to ACHD care.
The initial patient evaluation. Patients may first present for CHD care in their adult years because they have new symptoms, functional deterioration, or a growing sense of the need to resume regular care.

An ACHD specialist should evaluate all adults with moderate and complex CHD (Tables 4 and 5 of Task Force #1) at least once and should also evaluate most patients with simple CHD (Table 6 of Task Force #1). The evaluation should include a thorough history, a review of documents outlining specific diagnoses and details of treatments applied, and any other clinical problems. In addition, a tailored clinical and laboratory evaluation should be performed to assess current patient status. This initial ACHD evaluation should also involve an extensive component of patient education regarding both the nature of the congenital abnormality and the anticipated unrefaired or postoperative course, along with instructions on when and how to access care in the future, especially in urgent situations. This consultation should result in a report to patients and their primary care and supporting physicians. This report will document the baseline evaluation and provide a contact for questions and other issues that may arise in the future. The initial ACHD evaluation allows stratification of these patients according to risk and management difficulty.

An ACHD cardiologist will review the history regarding acquired cardiovascular and other medical conditions. This should be part of each work-up and will increase in importance as a patient ages. For example, the development of coronary artery disease or high blood pressure is important not only in itself but also in its potentially adverse effect on the course of CHD in adults.

Long-term follow-up. Most ACHD patients will require intermittent regular evaluations at a regional ACHD center. Such patients will benefit by maintaining contact with a primary care physician and, in some cases, a local adult medical cardiologist. All reports generated at regional ACHD centers should be transmitted to patients and their local physicians and should include specific goals and responsibilities for local as well as regional ACHD follow-up. In some cases, when a patient lives close to a regional ACHD center, the ACHD cardiologist can function as a primary cardiologist, leaving other health care to the primary care physician.

It is not implied here that the regional ACHD center take over the care of all ACHD patients. The role of the regional center should be to take an appropriate role in the management of each patient (ranging from no role, through joint care, to exclusive and close care). In addition, it should be used as a source of expert advice and information.

For simplicity, three groups of patients are described according to the following scheme:

Lesions that can usually be cared for in the Community (Table 6 of Task Force #1) after initial expert evaluation, usually in a regional ACHD center. These patients with simple CHD are felt to be at low risk for new clinical problems. This group includes some patients with minor congenital abnormalities who have not undergone surgical or other intervention (e.g., mild pulmonary valve stenosis, small isolated ventricular septal defect) and patients with simple congenital defects who have undergone successful repair (e.g., repaired ductus arteriosus, ventricular septal defect or secundum atrial septal defect with no residual shunt or other sequelae). Patients in this category will usually be followed by either a primary care physician or a community cardiologist. If necessary, a patient could be referred to a regional ACHD center.

Adults with CHD with residual hemodynamic or structural abnormalities who are clinically stable (Tables 4 and 5 of Task Force #1). Most adults with moderate and complex CHD fall into this category. Each specific defect or combination of defects carries its own list of potential complications. Such patients require ongoing surveillance to detect any changes in status and/or increased risk profile. In addition, as clinical practice and research advance, new principles of patient management will be applied by the ACHD cardiologist at the regional ACHD center. Such patients benefit, as well, from care given by a primary caregiver who provides local ongoing care and who communicates and cooperates with the ACHD cardiologist. For some patients, clinical evaluations may alternate between the local provider and the regional ACHD center.

Adults with CHD may develop active cardiovascular problems or become clinically unstable. These problems should be addressed, whenever possible, at a regional ACHD center. The ACHD cardiologist should maintain primary clinical responsibility for these patients until their clinical status stabilizes. Examples include significant arrhythmias, ventricular dysfunction, significant valve regurgitation, and infective endocarditis. Interventions in such patients generally should be performed at regional ACHD centers.

Any adult with CHD who develops a new clinical problem that might be related to a cardiovascular abnormality should be referred for re-evaluation to, or be under the care of, a regional ACHD center. In addition, if intervention is required, most patients should be evaluated at their regional ACHD center before intervention. When appropriate, some procedures can be performed locally (for example, noncardiac surgery in an asymptomatic low-risk adult with CHD). Such an evaluation might also lead to a recommendation that the intervention be performed at a regional facility integrated with the regional ACHD center.

FREQUENCY OF PATIENT FOLLOW-UP

For adults with CHD in the lowest risk group (Table 6 of Task Force #1), routine cardiac follow-up is recommended every three to five years as a rule.

The larger group of adults with moderate and complex CHD (Tables 4 and 5 of Task Force #1) requires more frequent follow-up, generally every 12 to 24 months. Such evaluation should include a detailed history and clinical
examination. Diagnostic studies should be standardized, with performance of more extensive evaluations (e.g., cardiopulmonary/metabolic stress testing, cardiac MRI, cardiac catheterization) based on the individual patient’s clinical course and findings. Part of such evaluations should include the detection of any new or progressive cardiac problems, patient education, and education of the primary care physician.

Finally, a smaller group of adults with CHD with complex anatomy and physiology require serial follow-up and examination at a regional ACHD center every 6 to 12 months, if not more frequently. This patient group includes adult patients with conditions such as single ventricle physiology, a morphologic right ventricle functioning in the systemic circuit, recalcitrant heart failure, recurring arrhythmias, and pulmonary vascular obstructive disease.

URGENT/EMERGENCY CARE

Most adults with CHD should wear medical alert devices and/or carry on their persons information that focuses on issues such as major diagnoses, the use of prosthetic valves or devices, anticoagulation, or other key points.

Emergency medical personnel at regional ACHD centers must be able to provide acute care for adults with CHD. The following situations and conditions go beyond the routine competence of many ER physicians and surgeons: intracardiac or intravascular shunts, pulmonary vascular disease, right ventricular dysfunction, and high-risk pregnancy.

Hospitalization for medical or cardiac acute care. Adults with moderate or severe CHD will usually require transfer to a regional ACHD center for urgent or acute care. This group includes patients with:

- Important intracardiac shunting;
- Greater than “mild” pulmonary vascular disease;
- Greater than “moderate” left ventricular or “mild” right ventricular dysfunction or failure;
- A systemic right ventricle;
- Single ventricle physiology;
- Greater than “mild” obstructive intracardiac valvular or vascular disease, including peripheral pulmonary artery stenosis or aortic coarctation, and excluding isolated aortic valve and many isolated mitral valve patients;
- Important congenital coronary arterial abnormalities;
- Pregnancy in the setting of important CHD;
- New onset of symptomatic tachyarrhythmias requiring institution of antiarrhythmic medication or ablation therapy, or bradyarrhythmias that include AV block or symptomatic sinus node dysfunction, in any of the patients listed above, repaired or un repaired.

Non-emergent hospitalization should be based on the same general principles outlined above. Patients with moderate and complex lesions will often require longer and more costly admissions than other types of patients.

INTERVENTIONS

The increasing complexity and procedural requirements for adults with CHD is reflected in their greater than 60% prevalence of prior cardiac operations and their nearly 50% need for re-operation or interventional therapy at some point during adulthood. A review of hospitalizations over the past five years in one center with particular expertise in catheterization of adults with CHD revealed that 26% are non-procedural, 57% involve catheterization and 17% involve surgery. The unique and increasingly complex needs of adults with CHD mandates centralization of procedural care.

TREATMENT OUTCOMES

The evaluation of structure and process requires that the best approach be determined. Ideally, this determination should be based on strong evidence. Expert consensus is necessary when evidence is lacking, but it should not be considered a fair substitute for rigorously performed clinical studies. The field of ACHD faces substantial challenges in generating the evidence needed to define what the “best practices” are. Patient groups are heterogeneous both between and within disease categories. The numbers of patients within particular categories of CHD tend to be small. The need for long-term follow-up in assessing clinical outcomes will delay the evaluation of the effects of new technologies and treatments.

The measurement of outcomes is an appropriate indicator of quality because it is the composite result of what is achieved with both structure and process. Outcomes should be systematically tracked, evaluated, and improved; and outcome data can be used to identify opportunities to improve practice.

Caregivers for adults with CHD, in coordination with third-party payers and regulators of access to health care, have a unique opportunity to construct and effectively utilize data sources, in concert with other non-caregiver-established databases (e.g., Medicare). In such a fashion, questions asked by patient advocacy groups, caregivers, and payer/insurers concerning optimal care strategies and esti-
mates of resource needs and utilization can be effectively addressed.

RECOMMENDATIONS

- Care of adults with CHD should be coordinated by regional ACHD centers that represent a resource for the medical community.
- An individual primary caregiver or cardiologist without specific training and expertise in adult CHD should manage adults with moderate and complex CHD only in collaboration with a physician with advanced training and experience in caring for adults with CHD.
- Every academic adult cardiology/cardiac surgery center should have access to a regional ACHD center for consultation and referral.
- Every cardiologist should have a referral relationship with a regional ACHD center.
- Approximately one regional ACHD center should be created to serve a population of 5 to 10 million people, with 30 to 50 such centers in the U.S.
- Within a single urban center, institutions should establish collaborative relationships.
- Each pediatric cardiology program should identify the ACHD center to which the transfer of patients will be made.
- An ACHD specialist should evaluate all adults with moderate and complex CHD at least once. The initial ACHD evaluation allows stratification of these patients according to risk and management difficulty.
- Adults with moderate and complex CHD will require regular evaluations at a regional ACHD center and will benefit from maintaining contact with a primary care physician.
- For adults with CHD in the lowest risk group (simple CHD), cardiac follow-up is recommended at least every three to five years. The larger group of adults with moderate and complex CHD will require more frequent follow-up, generally every 12 to 24 months. A smaller group of adults with very complex or unstable CHD will require follow-up at a regional ACHD center at a minimum of every 6 to 12 months.
- Every adult with CHD should have a primary care physician. To ensure communication, current clinical records should be on file both at a regional ACHD center and with the primary care provider (patients should also have copies of relevant records).
- All emergency care facilities should have an affiliation with a regional ACHD center.
- Patients with moderate or complex CHD require admission or transfer to a regional ACHD center for urgent or acute care.
- Most cardiac catheterization and electrophysiology procedures for adults with moderate and complex CHD should be performed in a regional ACHD center with appropriate experience in CHD, and in a laboratory with appropriate personnel and equipment. After consultation with staff in regional ACHD centers, it may be appropriate for local centers to perform such procedures.
- Surgical procedures in adults with CHD as outlined in Tables 4 and 5 of Task Force #1 should generally be performed in a regional ACHD center with specific excellence in the surgical care of CHD.
- Each regional ACHD center should participate in a medical and surgical database aimed at defining and improving outcomes in adults with CHD.
- Each regional ACHD center should encourage all ACHD patient data to be included in a national CHD database. Programs should work collaboratively on multicenter projects and develop investigator-initiated research proposals dealing with ACHD.
- The American College of Cardiology should recommend to the NHLBI and/or Agency for Health Care Research and Quality the formation of adult congenital centers for documenting and improving outcomes, education, and research.
- Each regional ACHD center should establish or affiliate with a patient advocacy group.