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TASK FORCES

Task Force 1: The Changing Profile of Congenital Heart Disease in Adult Life

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The extraordinary advances in cardiac surgery, intensive care, and noninvasive diagnosis over the last 50 years have led to an enormous growth in the U.S. and throughout the world in the number of adults with congenital heart disease (CHD). Approximately 85% of babies born with cardiovascular anomalies can expect to reach adulthood, and with continued improvement in surgical technique, this could increase further in the next two decades (1). In Canada, it is estimated that the number of survivors with adult congenital heart disease (ACHD) will increase from 94,000 in 1996 to 124,000 by the end of 2006. Although there is a general recognition that there are large numbers of adults with CHD in the U.S., accurate statistics are lacking. Reported prevalence rates of CHD in newborns vary widely and depend, to some extent, on lesion inclusion and exclusion criteria. For example, some studies include ventricular septal defects (VSDs); however, about two thirds of these individuals no longer have a VSD by adult age. Many studies exclude bicuspid aortic valves, which are present in 1% of live births. In addition, different methods of ascertainment (e.g., physical examination, echocardiography, registry data) yield varying prevalence rates of CHD in infancy.

A recent English study (2) reviewed all births in one health region (Newcastle) between 1985 and 1994, and noted 1,942 cases of CHD in a population of 377,310 live births (incidence of 5.2 per 1,000). Of these newborns, 1,514 were predicted to survive ≥16 years. Because additional diagnoses are sometimes made later in childhood, at least 2,192 children were expected to survive ≥16 years. Also, an estimated 784 would require follow-up in adult life. These figures predict the need for follow-up of adults with CHD, for >200 cases per 100,000 live births, or >1,600 cases every year in the U.K. (assuming a population of 50 million). Assuming a population of 280 million in the U.S., that would mean an increase of 8,960 adult cases annually, or 89,600 cases in the current decade.

Most studies from the mid 1980s onward, however, as well as more recent Canadian studies, report the number of CHD births to be close to 10 in 1,000 live births (3). Defining the exact size and composition of this population in adulthood is challenging, because data are lacking. An important mandate of this Bethesda Conference is to estimate patient numbers, which are essential for program planning and resource allocation. On the basis of the U.S. census data, the documented birth rates from 1940 to 1989 were averaged (Tables 1–3). The diagnoses corresponding to complex, moderate, and mild lesions are shown in Tables 4 through 6, and are those used by Task Force 4. Based on a documented incidence of 1.5 in 1,000 live births for complex CHD (Table 1) and by extrapolating likely survival rates for the early through more recent years, the approximate numbers of survivors in this group were derived. The incidence of 1.5 in 1,000 live births was based on the large New England Regional Infant Cardiac Program (NERICP) review of catheterization data, surgical findings, and postmortem diagnoses (4). Using this approach, ~117,000 adults with truly complex CHD are estimated to live in the U.S. in the year 2000. With improved surgical techniques, this number can be anticipated to increase over the next decade.

Using a similar model, Table 2 demonstrates the anticipated survival, to the year 2000, of patients with moderate CHD, as defined in Table 5. A prevalence of 2.5 in 1,000 is derived from published data on children, as well as some patients who began with more simple lesions but acquired complications (e.g., VSD with valve lesions, patent ductus arteriosus causing left heart dilation) (Table 7). These estimates predict an adult population of 302,000 with moderate CHD by the year 2000 in the U.S.

Estimating the number of adult patients with simple CHD (Tables 3 and 6) is more difficult. To utilize the absolute prevalence of simple lesions detected in infancy would grossly overestimate the number of adult survivors, because most VSDs will have closed by adulthood, and these patients will no longer be considered to have CHD. Thus, there will be considerable "attrition" of the numbers of patients with VSDs between the incidence at birth and the prevalence in adulthood. Most patients with a patent ductus arteriosus will undergo surgical or spontaneous closure in childhood (by definition, therefore, remaining "simple"), but a small proportion will remain patent, many needing closure, and are therefore defined as "moderate" cases. By utilizing these assumptions (Table 7), the prevalence of these lesions is derived: ~2.2 in 1,000. Thus, the estimated survival of patients with simple CHD in the U.S. to the year 2000 is 368,800. A conservative estimate of the total number of survivors—combining the mild, moderate, and complex subgroups—is 787,800. The addition of those with isolated bicuspid aortic valves would dramatically

Table 1. Estimated Prevalence of Complex Congenital Heart Disease in the U.S.

Year of Birth	Birth Rate/ Years	Prevalence (1.5/1,000)	Survival Rate (First Year)	Survival Rate (to Year 2000)
1940–1959	3 million	4,500	20%	10%
	× 20 years	90,000	18,000	9,000
1960–1979	4 million	6,000	65%	50%
	× 20 years	120,000	78,000	60,000
1980–1989	4 million	6,000	85%	80%
	× 10 years	60,000	51,000	48,000
Totals			147,000	117,000

increase this number. The moderate and complex subgroups—totaling 419,000 patients—need periodic (e.g., every 6–24 months) follow-up in a regional ACHD center.

These figures may well be underestimates for two important reasons. First, they are based on the incidence of CHD presenting in infancy and childhood, but *at least* 10% of cases seen in an ACHD clinic (in particular, secundum atrial septal defect, Ebstein's anomaly, and congenitally corrected transposition) are not diagnosed until adulthood. In addition, increasing numbers of immigrants to the U.S. add to the patient population. Therefore, a conservative estimate of patients needing periodic follow-up at a regional ACHD center is ~400,000. Although these predictions, again, are based on several assumptions, they provide a framework to estimate current and future resource requirements necessary to provide optimal care.

This population growth is also reflected in the growth of individual regional ACHD centers. In Toronto, a 269% expansion in the outpatient work load was noted over a 10-year period between 1987 and 1997. Similarly, an increase in the number of admissions to a large ACHD unit in the U.K. is shown in Figure 1. Notably, these admissions continue to increase, particularly for patients >30 years of age; by 1996, 30% of patients admitted were >40 years of age.

DISEASE PATTERNS

Data on the basic diagnosis and age of outpatients in a large unit in the U.K. in 1997 are also presented (Figs. 2 and 3). Complex lesions, such as tricuspid atresia and single-ventricle physiology, are well represented in patients >20 years of age, particularly in those >30 years of age, in current ACHD centers. The age range of patients seen in two large clinics is shown in Figure 4; they were older in the Mayo Clinic than in the Toronto series, where 50% versus 30% of patients were ≥40 years of age. These more complex patients are obviously vulnerable to additional acquired co-morbidities that impact both their cardiac and medical care, including hypertension, pulmonary, renal, and myocardial disease, and coronary artery disease. It is estimated that ~55% of the adult patient population is at medium to high-risk (defined as those at significant risk for premature death, re-operation, and complications) and thus need to be seen regularly in ACHD regional centers and followed for life. These patients include those with atresia, single-ventricle physiology, transposition variants, Ebstein's anomaly, tetralogy of Fallot, pulmonary vascular disease, and complex septal defects. Periodic review at a regional ACHD center continues to offer advantages over a general cardiac evaluation, particularly regarding the timing and type of intervention, follow-up strategy, and general recommendations (5). Approximately 45% of patients with mild defects, such as a small VSD or mild pulmonary valve stenosis, will not require regular follow-up in a regional ACHD center, but might benefit from at least one review at such a center at the discretion of the patient's physician.

The profile of this patient population will change over the next few decades, not only because of advancing age, but also with improved survival of patients with complex anomalies. In addition, with the impetus to perform definitive repair at an earlier age and with changing operative procedures, there will be changes in the anticipated disease patterns. Many adult survivors will have different hemodynamic and cardiac problems from those currently seen. For example, an infant with transposition of the great arteries

Table 2. Estimated Prevalence of Moderate Congenital Heart Disease in the U.S.

Year of Birth	Birth Rate/ Years	Prevalence (2.5/1,000)	Survival Rate (First Year)	Survival Rate (to Year 2000)
1940–1959	3 million	7,500	60%	55%
	× 20 years	150,000	90,000	82,500
1960–1979	4 million	10,000	70%	65%
	× 20 years	200,000	140,000	130,000
1980–1989	4 million	10,000	90%	90%
	× 10 years	100,000	90,000	90,000
Totals			320,000	302,500

Table 3. Estimated Prevalence of Simple Congenital Heart Disease in the U.S.

Year of Birth	Birth Rate/ Years	Prevalence (2.2/1,000)	Survival Rate (First Year)	Survival Rate (to Year 2000)
1940–1959	3 million	6,600	95%	90%
	× 20 years	132,000	125,400	118,000
1960–1979	4 million	8,800	95%	95%
	× 20 years	176,000	167,200	167,200
1980–1989	4 million	8,800	95%	95%
	× 10 years	88,000	83,600	83,600
Totals			376,200	368,800

will no longer have a Mustard or Senning procedure (with its late problems of systemic ventricular dysfunction and arrhythmias), but might be anticipated to have an arterial switch procedure and encounter quite different cardiac sequelae in adult life. Patients with complex single-ventricle physiology and various modifications of the Fontan procedure will increase in number. Perhaps with refinements in noninvasive diagnosis and earlier definitive repair of shunt lesions, the prevalence of pulmonary vascular disease and Eisenmenger syndrome in the adult population could be expected to diminish. These patients with complex malformations are subject to more diverse and numerous late complications and must be seen regularly at a regional ACHD center, to which they should have direct access. They need more intensive follow-up and probably more frequent re-evaluations and interventions.

SPECIAL RESOURCES

Impact of cardiac surgery. In the largest congenital cardiac center in the U.K., one in five admissions was for cardiac surgery. The Society of Cardiothoracic Surgeons of the U.K. Registry for 1998/1999 reports that in the U.K., 3,836 congenital heart operations were performed, with a mortality rate of 4.7%. There were 339 patients ≥16 years of age, with a mortality rate of 2.1%, but the data were not stratified according to low- and high-volume units, nor were they audited.

Some centers reported a surprisingly low number of ACHD operations per year, although expertise is often focused in centers where the same surgeons operate on both pediatric and adult patients, so the numbers can be combined. Previously published data from Stark et al. (6) have shown that mortality is higher in centers with lower operative volume, highlighting the risk of performing the "occasional" operation on adult patients with CHD.

It is estimated in the U.S. that 20,000 operations for CHD are performed every year. Based on pediatric data, low-volume centers have a higher mortality. The outcome is likely to be worse for adult patients who do not always have the benefit of a surgeon with special expertise and training in CHD. It is important, both medically and financially, to concentrate resources and funding and place patients in specialized centers. A close collaboration is necessary between experienced and trained cardiologists, echocardio-

Table 4. Types of Adult Patients With Congenital Heart Disease of Great Complexity*

- Conduits, valved or nonvalved
- Cyanotic congenital heart (all forms)
- Double-outlet ventricle
- Eisenmenger syndrome
- Fontan procedure
- Mitral atresia
- Single ventricle (also called double inlet or outlet, common or primitive)
- Pulmonary atresia (all forms)
- Pulmonary vascular obstructive diseases
- Transposition of the great arteries
- Tricuspid atresia
- Truncus arteriosus/hemitruncus
- Other abnormalities of atrioventricular or ventriculoarterial connection not included above (i.e., crisscross heart, isomerism, heterotaxy syndromes, ventricular inversion)

*These patients should be seen regularly at adult congenital heart disease centers. Modified from Connelly MS, et al. Canadian Consensus Conference on Adult Congenital Heart Disease, 1996. Can J Cardiol 1998;14:395–452.

Table 5. Types of Adult Patients With Congenital Heart Disease of Moderate Severity*

- Aorto-left ventricular fistulae
- Anomalous pulmonary venous drainage, partial or total
- Atrioventricular canal defects (partial or complete)
- Coarctation of the aorta
- Ebstein's anomaly
- Infundibular right ventricular outflow obstruction of significance
- Ostium primum atrial septal defect
- Patent ductus arteriosus (not closed)
- Pulmonary valve regurgitation (moderate to severe)
- Pulmonic valve stenosis (moderate to severe)
- Sinus of Valsalva fistula/aneurysm
- Sinus venosus atrial septal defect
- Subvalvar or supravalvar aortic stenosis (except HOCM)
- Tetralogy of Fallot
- Ventricular septal defect with
  - Absent valve or valves
  - Aortic regurgitation
  - Coarctation of the aorta
  - Mitral disease
  - Right ventricular outflow tract obstruction
  - Straddling tricuspid/mitral valve
  - Subaortic stenosis

*These patients should be seen periodically at regional adult congenital heart disease centers. Modified from Connelly MS, et al. Canadian Consensus Conference on Adult Congenital Heart Disease, 1996. Can J Cardiol 1998;14:395–452.
HOCM = hypertrophic obstructive cardiomyopathy.

Table 6. Types of Adult Patients With Simple Congenital Heart Disease*

Native disease
Isolated congenital aortic valve disease
Isolated congenital mitral valve disease (e.g., except parachute valve, cleft leaflet)
Isolated patent foramen ovale or small atrial septal defect
Isolated small ventricular septal defect (no associated lesions)
Mild pulmonic stenosis
Repaired conditions
Previously ligated or occluded ductus arteriosus
Repaired secundum or sinus venosus atrial septal defect without residua
Repaired ventricular septal defect without residua

*Those patients can usually be cared for in the general medical community.
Modified from Connelly MS, et al. Canadian Consensus Conference on Adult Congenital Heart Disease, 1996. Can J Cardiol 1998;14:395–452.

graphers, interventional cardiologists, surgeons, and anesthesiologists, with well-trained nurses on every team. The expert surgical care provided to children with cardiac anomalies must also be provided to adults. Re-operations are frequent, and the overall mortality is higher in patients having a re-operation versus a first operation (7). In one U.S. center (Mayo Clinic) following >1,800 patients, 1,243 of whom had cardiac surgery, almost 50% had two or more operations and 290 (23%) had three or more operations. This necessity for re-operation (particularly in patients with bioprosthetic valves and extracardiac conduits), again emphasizes the need for special surgical expertise in CHD. The types of operations in adult patients in a single center (Mayo Clinic) by diagnosis and age are shown in Table 8.

Operative mortality varies according to the basic diagnosis, the type of surgical repair, and the complexity of the anatomy. Re-operation poses technical difficulties for the surgeon because of adhesions (especially between the heart, aorta or conduit, and sternum), lack of retrosternal space, loss of anatomic landmarks (especially the coronary arteries) or the development of collateral vessels. In addition, there may be deleterious effects of all previous bypass operations on long-term myocardial function. Cyanotic patients face a higher mortality and more postoperative complications.

Table 7. Estimated Prevalence of Simple Congenital Heart Lesions in Infancy, as Compared With Prevalence in Adulthood

	Prevalence in Infancy (per 1,000)	Estimated Prevalence of Simple Lesions in Adulthood (per 1,000)
VSD*	3	0.3
PDA†	0.6	0.5
ASD‡	0.9	0.6
PS§	0.6	0.5
AS	0.3	0.3
Totals	5.4	2.2

*Most ventricular septal defects (VSDs) are closed by adulthood and are no longer a problem (i.e., the patients no longer have a "lesion"). †Most patent ductus arteriosi (PDAs) close spontaneously or are closed in childhood, and therefore remain in the "simple" category. ‡Most atrial septal defects (ASDs) are closed in childhood, and therefore remain in the "simple" category. §Most pulmonary stenoses (PS) remain in the "simple" category; some will become moderate or severe; and some will develop pulmonary regurgitation, and therefore be defined as "moderately complex."
AS = aortic stenosis.

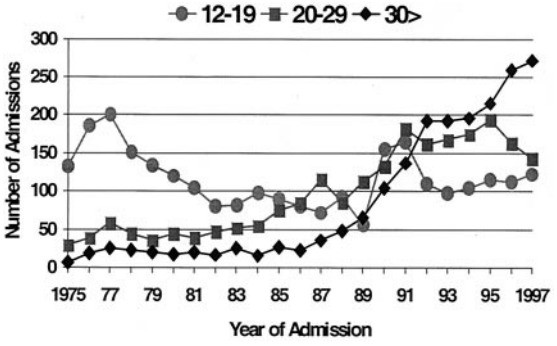

Figure 1. Age range of patients with CHD at hospital admission in a single center from 1975 onwards. The unit was opened as an adolescent unit in 1975 at the National Heart Hospital, joined by the Royal Brompton Hospital in 1990. Statistics from Jane Somerville, London, U.K.

Increasing age is associated with a higher mortality because additional co-morbid factors (as outlined previously) increase the operative risk. A detailed preoperative evaluation performed by an experienced medical and surgical team is essential. Transthoracic and transesophageal echocardiography, cardiac catheterization, and magnetic resonance imaging are necessary complementary tools to help the physicians make appropriate decisions. Holter monitoring and electrophysiologic study may determine if significant arrhythmias are present. Adults often report that they are asymptomatic as they adapt to their chronic condition and do not exercise beyond their limits. Exercise testing, critical evaluation of the patient's functional class, and assessment of ventricular function will help to determine the timing, risk, and success of the operation.

Transplantation is sometimes needed when the cardiac anatomy is not suitable for an operation or when ventricular dysfunction is too severe. The indications for transplantation are similar to those in patients with other cardiac conditions, and should be considered in patients who have New York Heart Association functional class IV symptoms, despite optimal medical therapy and in the absence of other therapeutic options. The number of adults with CHD requiring heart transplantation is currently relatively small, and an even smaller group has been reported with heart and

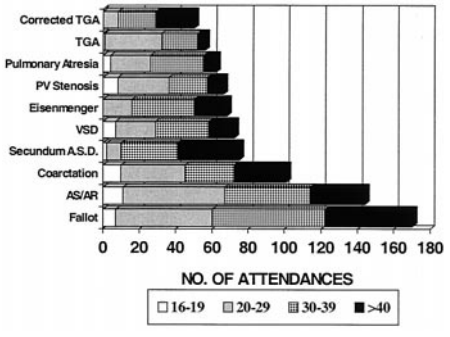

Figure 2. Outpatient attendance for 1997, according to age >16 years, basic diagnosis, and age. AR = aortic regurgitation; AS = aortic stenosis; ASD = atrial septal defect; PV = pulmonary valve; TGA = transposition of the great arteries; VSD = ventricular septal defect. Statistics from Jane Somerville, London, U.K.

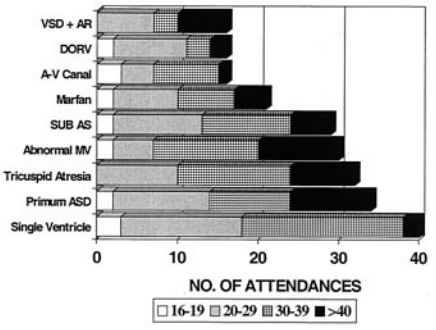

Figure 3. Outpatient attendance for 1997, according to age >16 years, basic diagnosis, and age. AR = aortic regurgitation; ASD = atrial septal defect; A-V = atrioventricular; DORV = double-outlet right ventricle; MV = mitral valve; SUB AS = subaortic stenosis; VSD = ventricular septal defect. Statistics from Jane Somerville, London, U.K.

lung transplantation. Transplantation in adults with CHD has been most frequently performed in patients with Fontan-type repair, transposition of the great arteries after a Mustard or Senning procedure with severe systemic (morphologically right) ventricular dysfunction, congenitally corrected transposition with ventricular dysfunction, severe Ebstein's anomaly or Eisenmenger syndrome. Transplantation needs may also increase in the next two decades, as more children with complex single-ventricle physiology undergo Fontan-like repair.

Electrophysiology. There is a growing recognition that arrhythmias, both atrial and ventricular, are an increasing problem in terms of management in these patients, and they are often associated with increasing morbidity and mortality. This is a consequence of: 1) underlying anatomic abnormalities; 2) chamber dilation and progressive fibrosis; 3) previous surgical incisions; and 4) compromised hemodynamic status. Pharmacologic management options for these patients may be limited by concomitant sinus node dysfunction, significant associated systemic ventricular dysfunction, and the desire for pregnancy.

Over last few years, newer, nonpharmacologic management options have emerged, specifically: 1) catheter ablation; 2) surgical approaches targeting structural abnormalities as well as offering intraoperative electrophysiologic ablation; and 3) automatic implantable internal defibrillators and a new generation of pacemakers with algorithms designed to prevent and treat atrial tachyarrhythmias. With some exceptions, in this population catheter ablation has met with only modest success so far; it is anticipated that ongoing refinements of mapping and ablation techniques will result in improved outcomes. A combined surgical approach has been employed successfully in the management of atrial arrhythmias, including those in patients with Ebstein's anomaly and patients undergoing Fontan revision, including the arrhythmias (both atrial and ventricular) seen after tetralogy of Fallot repair.

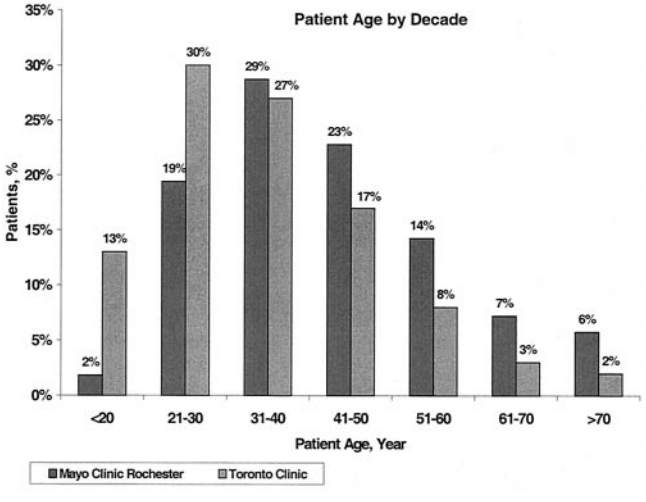

Figure 4. Age range of patients with CHD in two tertiary care centers.

Table 8. Cardiac Surgery for Congenital Heart Disease* by Major Diagnosis†

	Age ≥16 Years (n)
Atrial septal defect	131
Bicuspid aortic valves	129
Other diagnoses	28
Pulmonary atresia	23
Tetralogy of Fallot	20
Ebstein's anomaly	11
Transposition of the great arteries	10
Atrioventricular canal	9
Coarctation of the aorta	9
Double-outlet right ventricle	5
Anomalous pulmonary venous connection	4
Double-inlet left ventricle	4
Patent ductus arteriosus	3
Tricuspid atresia	2
Ventricular septal defect	2
Truncus arteriosus	1
Total	391

*Performed at the Mayo Clinic, Rochester, Minnesota, in 1999. †Includes all congenital diagnoses and all bicuspid aortic valve repairs.
The patients' mean age was 36.1 years (oldest patient 86 years).

These approaches, again, emphasize the desirability of a closely integrated collaboration between the surgeon, electrophysiologist, and cardiologist. With refinements in medical and nonpharmacologic therapy, it is anticipated that the need for arrhythmia therapy will increase in this aging population. The newer generation of atrial antitachycardia pacemakers and/or defibrillators will hopefully offer an expanded range of therapeutic options for these patients. However, issues of venous access, intracardiac shunts, and thromboembolic risk will often preclude a transvenous approach for lead implantation, and an epicardial approach may need to be considered. Data from current automatic implantable cardioverter-defibrillator trials in patients with ischemic or dilated cardiomyopathy appear to support expanded indications for automatic implantable cardioverter-defibrillator use in patients with substantial ventricular dysfunction, nonsustained ventricular tachycardia, and inducible ventricular tachycardia according to the electrophysiologic study. It is possible that these results may be extrapolated to adults with CHD, suggesting that the rate of

automatic cardioverter-defibrillator implantation will continue to increase in this patient population.

Catheterization/Intervention. Cardiac catheterization has been the diagnostic "gold" standard for CHD for the past 50 years. For the past 20 years, it has been increasingly supplemented by noninvasive diagnostic modalities; initially, cardiac ultrasound and, more recently, computed tomographic scanning and magnetic resonance imaging. Advances in these technologies have been logarithmic, and it is likely that in the coming decade, both morphologic and functional assessments of this patient population will be increasingly accomplished noninvasively.

Today, diagnostic catheterization is largely reserved for resolution of specific issues concerning operative interventions, including: 1) the preoperative evaluation of coronary arteries; 2) the assessment of pulmonary vascular disease and its response to vasoactive agents for planned, traditional surgical intervention and/or heart or heart/lung transplantation; and 3) as an adjunct to the noninvasive assessment of the morphologic and functional characteristics of many complex congenital lesions (e.g., delineation of arterial and venous anatomy, patients with heterotaxy, Fontan candidates, and patients who have had previous palliation in the form of a shunt). Such procedures should be performed by experienced and trained operators who maintain an adequate minimal volume annually.

Evaluation for possible interventional catheterization has become an increasingly common indication for diagnostic catheterization. For some lesions, notably valvular pulmonary stenosis, branch pulmonary stenosis, residual or recurrent aortic coarctation, and arteriovenous fistulae, catheter intervention is widely considered to be the treatment of choice. Coil or device occlusion of the patent ductus produces results comparable to those of surgical closure, and device closure of secundum atrial septal defects is often employed, although the success rate varies with operator expertise and the specific device used. It is likely that technical problems related to these devices will ultimately be overcome. Dilation of stenotic palliative shunts can obviate the need for re-operation, and transcatheter occlusion of shunts before repair of intracardiac lesions may simplify the surgical procedure. Along with the growth of interventional catheterization, there has been a renewed interest in small-incision cardiac surgery, and there will likely be continued advocacy for both management alternatives. Finally, a national and global perspective must be kept in mind, relative to limited resources in developing regions where interventional catheterization may provide partial or definitive treatment for many patients with CHD who do not have access to cardiac surgery.

Echocardiography. With improvements and refinements in echocardiographic technology, most adults attending an outpatient clinic undergo transthoracic echocardiography and, when necessary, complementary transesophageal echocardiography and magnetic resonance imaging. Two-dimensional imaging is more challenging in this patient population because of larger body size and often multiple previous surgical scars. The use of transesophageal echocardiography intraoperatively is also increasing, and it has been shown that it has a major impact on cardiac surgical procedures in 6% to 9% of cases (i.e., that it is desirable or necessary for the patient to resume cardiopulmonary bypass for revision of the cardiac procedure). Physicians interpreting these echocardiograms need to be experienced and have expertise in all aspects of CHD.

A high rate of diagnostic errors in pediatric echocardiograms performed in community-based adult laboratories has been reported (8). This study reported patients of varying ages, from one day to 18 years, and either interpretive or technical errors that were of major or moderate importance occurred in 53% of cases. There is reason to believe that in older patients, errors occur even more frequently because image acquisition is more challenging. Clearly, both expertise and technology are necessary to provide the best care.

Conclusions. The data, estimates, and models described herein emphasize that patients in the U.S. have been underserved by the present health care system. Over the next decade, a more comprehensive system must be developed for this growing population, with considerable collaboration between cardiologists specializing in pediatrics and adults. This Conference will facilitate the further recognition of these needs and hopefully help to develop the resources needed to achieve these objectives.

TASK FORCE 1 REFERENCE LIST

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