

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.

Task Force 5: Adults With Congenital Heart Disease: Access to Care

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INTRODUCTION

Access to optimal, specialized, appropriate health care, health and life insurance, and full employment remains a problem for many adolescent and adult patients with congenital heart disease (CHD) (1).

Health insurance may be difficult to obtain in adulthood because of “pre-existing conditions”—despite recent federal legislation—and because of uncertainties and misconceptions about the cost of care for adults with CHD. The actual costs of medical care appear to be relatively low in these patients compared with survivors of other chronic diseases

that begin in childhood (2). The costs in these patients, compared with the costs in age-matched patients with adult-onset disease of comparable severity, are unknown.

Federal regulation should provide the opportunity for individuals with disabilities to seek employment, the major source of health insurance coverage for most Americans. The Americans with Disabilities Act does not, however, require that insurance companies change their underwriting approaches or assessment of risk. Companies should not discriminate in hiring on the basis of increased health insurance costs incurred by the disabled.

Patients with CHD may have difficulty obtaining life insurance. Life insurance coverage is now generally more readily available for patients with CHD than it has been in the past. However, life insurance may be unavailable or require elevated premiums for patients with CHD, compared with age-matched control subjects, on the basis of their diagnosis. If financial gain or equity is an issue, alternatives such as savings plans, mutual fund plans, annuity policies, or other, more standard means of investment, may offer similar benefits.

Employment of adults with CHD in an appropriate position and at an appropriate level may require special counseling, for physical and psychosocial reasons. The use of professional job training, vocational rehabilitation, and similar services should be maximized. Recent legislation has attempted to ameliorate this problem for a broad variety of individuals, including those with a wide spectrum of medical disorders. However, full, appropriate employment remains an unfulfilled goal for many adults with CHD.

Organized, effective, and passionate advocacy for adolescents and adults with CHD has been lacking, especially when compared with that of other patients with congenital anomalies and diseases (e.g., National Organization for Rare Disorders, Genetic Alliance). Health care providers and patient groups at local, state, and national levels should intensify efforts to make the needs of these patients more visible and to seek innovative, effective solutions to problems of access.

Access to health care professionals trained appropriately to treat this patient population also remains a challenge. In some academic health centers, special clinics focusing on these patients have been established, but the capacity of these clinics is not adequate to accommodate this growing patient group, as discussed earlier in this Conference report. Access to specialized care in rural areas appears to be a particularly challenging problem.

COST

Data on cost of CHD: a multicenter study. There are relatively few studies defining the life-time costs associated with chronic diseases in children. In 1994, Garson et al. (2) described a multicenter assessment of lifetime costs of care for children with CHD. The study aimed to define total costs associated with the clinical cardiovascular-related care

for children with CHD. To accomplish this cost definition, the investigators employed clinical functional categories, with subcategories based on disease severity and treatment options. They also identified six large clinical care sites willing to participate in the collection of cost and clinical practice data, and they extrapolated lifetime costs on the basis of these data. Physicians in each of the six sites assigned typical clinical courses to each subcategory. The clinical outcome was defined by the frequency of seven services: routine clinic visit, complex clinic visit, hospital admission for medical treatment, hospital admission for surgical treatment, hospital admission for interventional treatment, hospital admission for pacemaker implantation, and number of years the patient has taken cardiac medication. Physicians were asked to estimate the percentage of patients who fell into each clinical category and the number of services they would need during the first 40 years of their life. Finally, they were asked to indicate the average charge for each of the services listed.

This study produced the first reliable data on cost and practice variation in pediatric cardiology. Both measures may be used as the basis for increasing control of clinical practice by a variety of influences (e.g., managed care, development of clinical practice guidelines).

Findings: cost and variability. This study provides factual data that can be used to estimate current and future health care costs. Average charges for care (birth to 40 years of age) varied from \$47,515 to \$73,606, or \$650 per year. A simple ratio of charges to mortality was calculated. Although in the early 1990s charges could be used as a surrogate of cost, this is no longer the case. However, the study provides statistics that should be of use to insurers and hospitals in projecting overall cardiovascular costs across a wide range of ages and diagnostic categories. It does not take into account noncardiovascular costs associated with the care of these children. For example, general pediatric care costs incurred by these children were not studied, nor were the costs of respiratory, physical, or occupational therapy and services providing care for children with disabilities, as well as other costs.

Although this study made considerable progress toward identifying cost/benefit ratios based on mortality, the cost/benefit ratios used to determine the validity of new treatment modalities must also include more refined measures of morbidity. The need for more refined definitions of morbidity will enhance the ability to define an optimal outcome. In addition, issues of psychosocial stability, education level, and employability will more adequately define the value of the investment in these children.

Garson et al. (2) also identified substantial variability in practice across institutions. Actual variability in total charges was not as great as practice differences would suggest. However, variability in practice patterns contributes to uncertainty of actual costs.

Some future challenges in assessing costs. YEARLY TREATMENT MODALITY AND OUTCOME VARIABILITY. Estimates of total service utilization in the study of Garson et al. (2)

were based on 1992 utilization. Patients born more recently may have a substantially different outlook from those born in the early 1970s or before. Thus, estimates of total costs of the study are most applicable to the present adult population and have less relevance to infants or children who are currently under care for cyanotic or acyanotic CHD.

SITE OF OUTPATIENT CARE AND INTERPRACTITIONER VARIABILITY. The utilization of services and the frequency of those services may depend on the site of care for adults with CHD. If a pediatric cardiologist cares for them exclusively, their care may be quite different from the care provided by an adult cardiologist, an internist, or an interdisciplinary group focused on adults with CHD.

COSTS BESIDES PHYSICIAN CARE. Only estimated direct medical care costs were included in the study of Garson et al. (2). Two significant costs were excluded: first, the costs to the family—loss of work (i.e., income) for parents, costs of uncovered medical services and drugs, costs of psychologists, and other costs. Second, there are the societal costs associated with loss of work, increased health care needs, and increased educational services. More data on the costs of care are needed. An update of the type of investigation conducted by Garson et al. (2) would be most helpful.

INSURABILITY

After over a decade of efforts to obtain insurance coverage for adults with CHD, some progress has been made, but not enough. Several possible reasons are suggested.

The population. The unique population of young adults with heart disease was projected to include over a million people as we entered the new millennium (3). It was estimated that, after cardiac surgery, 8,500 young adult patients reach adulthood each year (3). Many have chronic, symptomatic cardiac conditions; others are totally asymptomatic, with only mild congenital lesions, such as a small ventricular septal defect. Many have had surgery, some expecting further operations. As operative results and post-operative care continue to improve, the number of young adults with CHD will undoubtedly continue to increase. According to the Second Natural History Study, many patients classified into “simple” diagnostic categories are appropriately educated or employed, or both (4).

Types of insurance. **LIFE INSURANCE.** Although it is not necessarily considered the best long-term financial investment, life insurance is now considered less of a necessity than it was a few decades ago, because other investment vehicles are available. However, some families consider this a necessary component of their financial planning. Life insurance is now available to more young people with heart defects than it was in the past (1,5,6), but it is still more difficult to obtain for them, compared with individuals with no health problems (7). The implied risk associated with different defects is quite variable among different insurance companies. Some offer standard policies to patients who

have mild pulmonary stenosis or closed or small ventricular or atrial septal defects, while others increase the premium rate even for innocent murmurs. They also tend to offer policies more readily to patients who have passed their 15th birthday, assuming that passage from childhood lowers their risk. The cardiologist is often asked to write a letter to the insurance company about the patient's condition. The physician should do so, explaining the long-term expectations regarding the particular patient. In addition, the family should be encouraged to apply for insurance from several companies. Sometimes, using an independent agent will achieve the best results.

HEALTH INSURANCE. Presently, almost 45 million people in the U.S. do not have health care coverage. If the patient's family is fortunate enough to have health insurance, young adults with heart disease can be covered as a dependent until age 19, unless they are still in school or disabled. If more than half-time schooling is pursued, various companies' insurance coverage continues until the patient's 21st or 25th birthday. If the patient's status changes (e.g., by marriage), dependent coverage is often lost. Until age 18 to 21 years, patients may qualify, depending on income levels, for public programs such as Medicaid or State Title V, Children with Special Health Care Needs (CSHCN) Program. The name of these programs varies from state to state. For a directory of such programs, including program name, contact information, eligibility criteria, and scope of services, refer to the Directory of State Title V, CSHCN Programs: Eligibility Criteria and Scope of Services (2000 edition), by John Reiss and Diana Lamar (editors), Gainesville, Florida: Institute for Child Health Policy (<http://www.ichp.edu>). Others who qualify for Social Security (by virtue of being determined to be disabled) can obtain Medicare, Part A coverage, but must purchase Medicare, Part B for 80% physician services (20% co-pay).

Previous studies have indicated that between 10% and 22% of adults with CHD are uninsured, and 67% have reported difficulty in obtaining health insurance or changing jobs to guarantee coverage (8). Those with a history of surgical repair reported the greatest difficulty, although this may not correlate with their current severity of illness. Most commonly, patients can obtain insurance only after the exclusion of cardiac disease as a pre-existing illness, by paying higher premiums to participate in a high-risk reinsurance pool, or by obtaining coverage through their employer, in either a health maintenance organization or self-insured plan.

Types of coverage vary. The common type of coverage 10 to 20 years ago was an independent health care policy. Now most people have some form of group coverage, usually purchased through their employer. Most of these plans are “managed” (i.e., they are linked to a network of participating physicians and hospitals). In the most developed health maintenance organization, the choice of physicians is usually restricted to the network, and a primary care physician (“gatekeeper”) usually directs care by a specialist (e.g.,

cardiologist). The gatekeeper may be directed by an internally developed or nationally developed set of guidelines for specialty care referral. In the most rigid circumstances, the gatekeeper may be the health maintenance organization itself, which may actually direct the referral to the cardiologist of its choice. In a point-of-service plan or a preferred provider organization, patients can go freely out of the network to choose a specialist, with a plan-defined deductible and co-payment, representing a greater financial responsibility for the patient, compared with obtaining care within the network. Within this organizational framework, it may be difficult for adolescents or adults with CHD to access care by a skilled cardiologist who is either familiar with or has expertise in CHD. This can lead to under-utilization (withholding of specialty access or testing) or over-utilization (unnecessary testing performed by a cardiologist inexperienced in caring for adults with CHD).

There is a similar obstacle to the team concept that is crucial in the care of the adolescent and adult patient with CHD and associated or other health problems. Referral and reimbursement to multiple subspecialists and mid-level provider team members may be a new concept for the insurer, who may not understand and who may reject this option for the patient. There is a clear need to educate the insurer about this care delivery model, compared with the multidisciplinary model that is accepted by most insurers for the diagnosis and treatment of cancer.

In summary, the current managed care insurance model does not easily support what may be considered the optimal care of adults with CHD. There needs to be a recognition by insurers that the complex range of conditions and the care needs of adults with CHD are different from those of adults with acquired heart disease, and current referral and reimbursement models are inadequate to address these differences.

What can be done? In the early 1990s, the Council on Cardiovascular Disease in the Young, of the American Heart Association (AHA), held a conference on insurability of young adults with heart disease (3). Suggestions from that conference generally apply today and can still be considered.

As practice guidelines relevant to adults with CHD are developed, organizations such as the American College of Cardiology (ACC) should share and discuss these guidelines with insurers. Such guidelines should allow insurers to more accurately project costs of care and to develop appropriate premiums.

It was also suggested at the AHA conference (3) that companies use community standards in the development of premiums, rather than using small-group standards or a claims-made standard that penalizes a given patient or family. The use of clinical practice guidelines should encourage the appropriate use of technology, thus further controlling costs. Training programs should develop strategies to produce a cadre of adequately trained cardiologists who can provide optimal and cost-effective care to this

population. Uniform coding and billing processes would greatly reduce paperwork and office/hospital overhead.

Preventive care for pregnant women, which is often not available to the poor (9), could reduce some cases of CHD in newborns, as caused by the mother's alcohol and cocaine abuse, as well as infections that could have been prevented by immunization. Prevention of premature birth would also improve survival and decrease the incidence of some childhood diseases. Genetic counseling is also important for couples whose offspring are at increased risk of CHD.

Over the past two decades, patients have sometimes had to resort to drastic measures (e.g., quitting work, remaining in an unsatisfactory position) to maintain health insurance coverage. Unfortunately, some have elected to avoid clinic visits, catheterization, or operation because of the personal financial consequences. Some have died as a result; many have suffered an unnecessary decline in function. None of these choices is appropriate or fair.

Since State Title V CSHCN programs cover cystic fibrosis and hemophilia after the age of 21 years, why not do so for CHD? This is an avenue that should be pursued.

EMPLOYABILITY AND VOCATIONAL SUPPORT

Employment status. Reports of employment status of adults with CHD vary. No more than 10% are considered totally disabled. Those with a mild disability reported a 50% increased rejection rate in job applications, and those with a moderate-to-severe disability reported a 400% increase in rejections of job applications, in comparison with nondisabled control subjects. The severity of disability has been correlated with unemployment and lower income (10). There have been numerous assessments of employment status of adults with CHD in the last decade (10,11), with 8% to 13% receiving public assistance or living as a dependent with relatives.

U.S. federal regulations. Existing federal regulations provide for training and improved prospects for employment of people considered disabled (e.g., Vocational Rehabilitation Act). Subsequently, there have been further congressional acts barring employment discrimination by any federal employer or employer receiving federal funding (Rehabilitation Act of 1973); the U.S. Civil Service (Act of June 10, 1948) and the Americans with Disabilities Act (ADA of 1990), which extends this provision to the private sector, are two other such acts. Most recently, the Work Incentives Improvement Act was passed in 1999; this act provides for a stepped approach to less severely disabled individuals who could reasonably be expected to be functional and employable with assistance.

The Rehabilitation Act of 1973 also established affirmative action for the advancement of disabled persons, including hiring, placement, and vocational rehabilitation. It also provided for the National Council on the Handicapped to be formed within the Department of Health, Education and Welfare. This council was later granted the authority to

review all federal laws and programs regarding individuals with disabilities.

The ADA prohibits discrimination with respect to hiring, promotion, or discharge of employees on the basis of disability. Employers are also required to make accommodations, within reason, to allow a disabled employee to perform a job. Although the ADA specifically excludes insurance coverage practices from these injunctions, employers cannot deny employment on the basis of the coverage, or lack of coverage, provided by their insurance benefits, or because their cost of insurance would increase.

The Work Incentives Improvement Act allows for state-sponsored Medicaid programs to cover some adults who may be declared "disabled" by virtue of their underlying condition. The legislation allows states to define the list of conditions. Therefore, it is possible that a state could define adults with CHD as "disabled" and eligible for coverage; this would require each ACC chapter to work with state Medicaid programs and state legislators to define the eligibility. The ACC Advocacy Division has resources for chapters to help in this effort.

Strategies to assist in employment counseling. The most important element in employment counseling by the health care provider is an expert, realistic, and assertive estimate of the patient's physical capabilities as they relate to available vocational options. Once this is done, services such as vocational rehabilitation, job training, and physical rehabilitation can be offered. The practitioner should also strongly consider direct involvement with the employer, at the patient's request, to assist in an optimal match between patient capabilities and job requirements. Despite shortfalls in legislation and health care coverage, concerted efforts made by the health care provider can make an enormous difference in a specific patient's vocational experience.

ADVOCACY

The ACC has made a strong statement supporting access to cardiovascular care, regardless of a patient's ability to pay (12). Recently, a plan to achieve universal coverage by 2010 was the topic of the ACC Presidential Plenary Address; this has been published in the *Journal of the American College of Cardiology* (13). In the meantime, however, we have today's reality and must take incremental steps to provide coverage for this segment of the population.

Most of these patients are not severely disabled and are capable of working and contributing to society (8,14). Despite this, insurance coverage is denied, limited, or associated with unacceptably high premiums. For example, through state high-risk pools, premiums for these individuals may exceed standard premiums by as much as 50%, making this form of insurance inaccessible for many of the people who need it most. Indeed, as indicated previously, even those who have insurance face other issues, such as under-insurance, disapproval by managed care companies of specific medical services, and life-time caps on coverage.

This population of individuals is particularly vulnerable because they suffer from conditions they have had all or most of their lives. They have received coverage and treatment as children, only to have it taken away at a time in their lives when they are expected to become self-sufficient. To complicate matters, these patients, who are generally capable of working, often have difficulty finding employment because of their health history.

The ACC's legislative approach. The ACC leadership has met with staff at the White House, members of Congress, and numerous other specialty and patient organizations to discuss possible mechanisms for providing health insurance and job training to those with childhood diseases, including CHD. The ACC presented a resolution to the American Medical Association (AMA) House of Delegates; the AMA issued a report in December 1999 (15) encouraging the government to identify these individuals and the barriers to their care.

The ACC worked on a popular proposal introduced by Senator Edward M. Kennedy, D-Mass.; Senator James Jeffords, R-Vt.; and Rep. Rick Lazio, R-N.Y. Endorsed by the Administration, this legislation—the Work Incentives Improvement Act described earlier—provides an incremental approach to addressing the health insurance needs of the less severely disabled. The overriding intent of the legislation is to enable disabled individuals to return to work, but it also contains a provision that allows state demonstration projects for people who are less severely disabled and who, in the absence of needed health care services, would reasonably be expected to become disabled. The demonstrations specifically permit states to offer these individuals a Medicaid buy-in option. The ACC worked with legislators to add to the House Commerce Committee report accompanying the bill, language that clarifies the congressional intent of the proposal. The report's new language says that states could include in the definition of "potentially severe disability," those individuals with congenital birth defects or other diseases developed in childhood. The ACC key contacts were alerted, and they provided important support. The bill was signed into law in 1999. This is an important first step.

The role of ACC chapters. Individual ACC chapters are encouraged to take up this issue on behalf of patients with cardiac diseases. Already, individuals in some states are considering proposals to fulfill the impending mandates of the Work Incentives Improvement Act. The ACC has materials ready to assist chapters in assessing the scope of the problem in individual states and determining strategies for communicating with state officials.

The role of individual physicians. Our patients need us to advise them about what to expect in the real world. We should tell our patients before they enter adulthood that their health insurance coverage requires their attention and should be of concern; they should be advised to seek jobs, as appropriate, with large employers or the state or federal government. Our patients should understand that, under

law, their health status is to have no bearing on employment; therefore, employers are generally not permitted to inquire about their condition. This advice can help the patients we know, but we must also endeavor to help those we do not know, by working with our legislators to extend coverage to as many people as possible.

RECOMMENDATIONS

Based on the considerations outlined earlier, the Task Force recommends that the ACC take the following actions:

General

- Develop a strategic plan for organized advocacy for this patient population to include health care professionals, patients, and their families, in the context of a public relations campaign.

Insurance Coverage and Health Care Costs

- Develop educational materials to guide adolescent and adult patients in the transition to independence, including the need for health (and perhaps life) insurance, barriers that may exist in obtaining coverage, and strategies to obtain optimal coverage.
- Develop a better understanding of the true economic impact (e.g., payments, future income potential) of CHD in adults; this will involve sponsoring a multicenter study with economic forecasting.
- Include, in formal and regular discussions with insurance companies and other public and private payors and purchasers, information on the special problems encountered and expertise necessary in the care of adolescents and adults with CHD.
- Reduce the barriers to multidisciplinary services by developing innovative reimbursement methodologies. Pilot programs established between one or more ACHD centers and major payors (public and private) should be encouraged.
- Work, at the chapter level, with state legislators to specify CHD in a demonstration project of the Work Incentives Improvement Act.
- Recommend that physicians discuss individual patient coverage concerns with insurance company medical directors.
- Advocate health care coverage for all. As an incremental step, all adults with CHD should be covered, thus removing a significant barrier to access.

Education, Employability, and Vocational Counseling

- Develop additional educational materials to help adolescent and adult patients as they approach the job market, focusing on their legal rights (e.g., health should not be discussed during an interview), tips for success, and where to go for job training and vocational counseling.
- Recommend that, at the patient's request, individual physicians work directly with patients, their schools, and their employers or potential employers to optimize opportunities.

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