

Cardiology News

President, IMNG Alan J. Imhoff

HEART OF THE MATTER Caring for Adults With Congenital Heart Disease

As the cardiology community has become aware of the steadily growing number of adults with complex congenital heart disease over the past 2 decades, we've embarked on a multi-pronged effort to address the organization of care, the workforce needs, and the funding to increase the knowledge base in this area.

Now is a good time to look at how the landscape has changed since the 32nd Bethesda Conference in 2000 on "Care of the Adult With Congenital Heart Disease," to give ourselves a grade on our accomplishment, and to examine the factors that will facilitate future progress. It is particularly prescient to examine the needs of this population as a distinct chronic care model as we go stumbling forward in our efforts for health care reform.

The 32nd Bethesda Conference convened a panel of cardiologists, surgeons, health policy experts, and government (health care) administrators to define the broad outlines of health care delivery to the ACHD population. It proposed the organization of care into regional ACHD centers that could serve as home base for complex patients, support other providers throughout the region through consultation, train ACHD cardiologists, and advance the field through research. The conference also proposed specific training and funding requirements to meet workforce needs. So, what have we accomplished in the decade since that report? We have taken significant steps to carry out the vision of that conference, but we have not overcome one pervasive element that is continuing to hold back our progress. Accomplishments first, then challenges:

In regard to regionalization, the Adult Congenital Heart Association (ACHA), an organization of patients and health professionals, has developed a roster of self-designated ACHD centers and has an ongoing consensus project, Vision 2020, to define regional centers of care.

Preparation of the workforce has been advanced through several different actions. The new Adult Congenital and Pediatric Cardiology (ACPC) section of the American College of Cardiology provides a forum for pediatric and adult cardiologists and a catalyst for developing research teams, advocating criteria for third-tier subspecialty certification, and defining educational needs.

The development and publication of the ACC/American Heart Association Guidelines for the Management of Adults With Congenital Heart Disease in 2008, an ambitious project, provides guidance for the general cardiologist managing ACHD patients and indicates the best process for integration with ACHD regional centers (J. Am. Coll. Cardiol. 2008;52:143-263).

So, where do we stand?

We have seen an encouraging collaboration between pediatric and adult cardiologists with career interests in ACHD, but although there is increasing interest in this career track, the numbers of trainees entering this pathway is still small and some who have taken the additional years of training complain of the paucity of job opportunities. Why? Because disease burden and clinical need do not translate into full-time equivalents at medical centers. Most centers must focus increasingly on the bottom line. The ACHD population, on average, represents the younger end of the adult age spectrum and therefore, a higher proportion of the underinsured, making a poor business case for a center to support the appropriate infrastructure for individuals with so many special needs.

It should surprise no one that the major obstacle to the development of an appropriate system of care for ACHD patients comes down to money. This population is more complex, and needs highly specialized care. This is not a recipe for a profit center. It is, rather, a cost center. Yet I believe that our present system of non-care is ultimately more costly than an appropriate level of care. Patients with ACHD are more likely to be admitted for inpatient care through the emergency department. For the lack of proactive management, a patient with single ventricle may slip into unremitting failure and require heart transplantation decades before it's necessary.

We must look at the costs of the present system and propose a system of care for ACHD patients that will produce better results at no increase or even lower costs over the intermediate and long term. This is a unique population, with a complex profile, that has never before existed. ACHD patients are also, in general, at the beginning of their productive lives, so the differences in outcomes with proactive care will have a sustained impact on society.

If a case can be made for a sustainable business model, it will unleash all the great ideas that we have developed over the past decade. It is an interesting and compelling challenge to which I invite others to join in what should be a creative and meaningful effort. ■

DR. WILLIAMS, an editorial adviser to CARDIOLOGY NEWS, was chair of pediatrics at the University of Southern California, Los Angeles, Keck School of Medicine, until April of this year. She is on a yearlong sabbatical at the university to study the economics of life cycle coverage for patients with chronic childhood illnesses. DR. SIDNEY GOLDSTEIN will return to Heart of the Matter in August.

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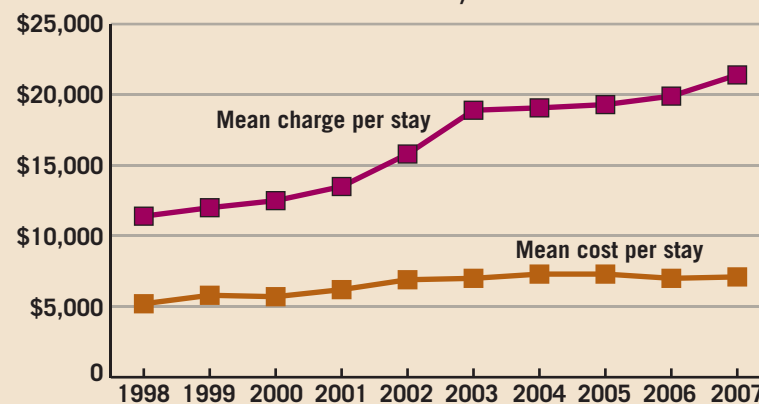


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VITAL SIGNS

Mean Hospital Bill for Uninsured Stays Went Up 88% While Cost Rose 37%, 1998-2007



Note: 1998-2006 hospital charges and costs noted in 2007 dollars.
Source: Agency for Healthcare Research and Quality