



## CARING FOR ACHD IN A MARKET-DRIVEN SOCIETY

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### Introduction

Our cardiology community is responding to the growing number of emerging adults with often complex congenital heart disease. Collaborations are springing up between adult and pediatric cardiologists, advanced practice nurses, patients, and families to address the health care, research, and advocacy needs for this population. Workforce and institutional needs are being defined and research collaborations are being formed. Meanwhile, health care reform is evolving through fits and starts with little predictability regarding its medium and long-term impact. Since ultimately finances trump philosophy, it is essential that we understand the financial underpinnings of healthcare delivery to patients with this unique model of chronic disease in order to carry out these plans.

What is unique about this population with chronic disease? The most obvious feature is that they have the potential of contributing to the GDP for 40+ years. Another is that for the more complex lesions, society has already invested a considerable amount to achieve survival into adult life. Finally, the period of early adulthood is relatively uneventful in terms of complications and resource utilization compared with early childhood and later adult life. Thus, the basic needs to maintain cardiovascular status and prevent secondary disability may be modest in comparison with treating some of the severe consequences of their disease, such as poorly managed valve regurgitation or arrhythmia that eventually requires costly solutions such as transplantation. It is important, therefore, to define the resource requirements and potential health outcomes of a healthcare system that would be designed for this population.

### The Status of CHD Patients

Patients with congenital heart disease (CHD) have access to comprehensive subspecialty care during early life; however, upon their 19th or 21st birthday (depending on the state), most patients will lose coverage from public-funded health plans such as Medicaid, which also supports hospital-based care coordination. Although recently, some private insurance companies have extended coverage for young adults as dependents up to age 26, many employers are limiting dependent coverage, blunting the impact of this recent healthcare legislation. Continued access to health care requires employment at a company that offers health insurance or the patient must be disabled enough to qualify for coverage under the Social Security Disability Program. But, depending on the extent and limitations of their disease, finding and securing a full-time job can be challenging, and few will be financially stable enough to purchase their own insurance. More than any other time, young adults are having a difficult time finding full-time employment.<sup>1</sup> Currently only 41% of all 18-29 year olds have full employment, down 9% since 2006. It is at this most vulnerable time when their insurance coverage is ending or changing that these young adults are transferring to a new provider.

The literature suggests that many such patients drop out of cardiology care for substantial time intervals and subsequently experience worsened health conditions later in life.<sup>2</sup> We propose that some complications could be avoided, delayed, or ameliorated by consistent prospective management during their early adult years. However, we know relatively little how the lack of transitional care impacts health and social outcomes of these young adults and what resource utilization would be required to maintain consistent and appropriate management of these chronic illnesses in the young adult population.

### The Costs of Secondary Prevention

The economic and social costs and benefits of secondary prevention for this particular cohort are not well understood. This gap in knowledge is partly due to constantly improving management in the past decades that has resulted in a new and sizable cohort of young adults with chronic conditions who differ substantially in complexity and function from previous groups. Average per-patient costs in the United States for managing adult congenital heart disease in 1992 dollars were \$18,773, but this cohort represented a population of patients that was not as complex as that currently entering young adulthood.<sup>3</sup>

We know that young adults ages 19–29 represent 17% of the U.S. population and 30% of the uninsured under age 65.<sup>4</sup> This is likely to worsen over the next decade. In a study by Callahan and Cooper, lack of insurance was directly associated with unmet medical needs in two-thirds of young adults with a disabling chronic disease, 45% of whom had no source of regular care.<sup>5</sup> In this study of 19–29 year olds with a disabling chronic disease (based on 2002 National Health Insurance Survey data), they were less likely than nondisabled young adults to be employed (45% versus 76%) and less likely to have private insurance (40% versus 65%). They also had a 20-fold greater likelihood of delaying or failing to get medical care due to cost. Social Security disability insurance will be available for the few who are disabled, meet the financial requirements, and have the resources and patience to provide the necessary documentation, but that does not address the larger proportion of individuals who are not severely symptomatic. Recent studies have shown that nondisabled youth (ages 15–25) with chronic disease who lose insurance coverage experience longer periods before insurance is regained than either disabled youth or youth without chronic disease.<sup>6</sup> Therefore, nondisabled youth are

at elevated risk for having a significant lapse in health care and, paradoxically, have the most to lose in terms of productive capacity.

A study by Gurvitz et al. revealed that patient admissions to hospitals in California were more likely to originate from the emergency department for patients over 17 years of age, indicating a significant unmet need for proactive management in the young adult group.<sup>7</sup> Furthermore, these hospitalizations were spread over a larger number of hospitals than in the pediatric age group, indicating a decentralization of care even though the 32nd Bethesda Conference: Care of the Adult with Congenital Heart Disease recommended concentration of care around high-resource centers.<sup>8</sup> The lack of organized care, the more reactive than proactive care, and the growing numbers of patients are likely to cause progressive increases in the cost of care. We know that hospital admissions in the United States for adults with CHD more than doubled between 1998 and 2005, and charges grew to an even greater degree.<sup>9</sup> Registries in the Netherlands show that hospital admissions for CHD were 2 to 3 times that of the general population.<sup>10</sup> This was most pronounced in older patients, with a median age of admission being 39 years. This emphasizes the importance of providing an effective and efficient system of care.

### Obstacles to Effective Care

At present, our system is a hodge-podge of cost avoidance. It is difficult enough for a mature adult to negotiate the impediments inherent in health insurance payments. Young adults have even fewer tools or temperament to deal with the frustrations of coverage and access to care. It is understood that executive planning functions do not fully mature until the mid-twenties or later in many individuals. Studies of young adults with diabetes have revealed unrealistic expectations of convenient, available health care.<sup>11</sup> Dropout from health care is the rule for young adults with many types of chronic disease such as heart disease or diabetes (even insulin-requiring patients). Even in Canada, where continuous state insurance is provided, nearly 50% of patients drop out of care for substantial periods of time,<sup>12</sup> reaching a rate of 61% after the 18th birthday;<sup>2</sup> clearly factors other than insurance are in play as well, such as inadequate access to appropriate workforce and psychosocial issues.

An important difference between the pediatric and adult health-care systems may partly explain this finding. Pediatric cardiology programs are provided state funding for care coordination for all patients with CHD by advanced practice nursing and social service while adult institutions do not have similar funding. With government-sponsored reimbursement cuts in the offing, providers and institutions will have even less ability to provide unreimbursed care. Moreover, because the numbers of patients are small and their diseases are complex and diverse, there are few or no economies of scale that can be exploited.

### The Road to Seamless, Sustainable Care

So, what might be a successful strategy to provide effective health care at practical and sustainable cost? Since a large proportion of health issues in the adolescent–young adult age group involve health and social behaviors, many of their needs may be best met by allied health professionals. Providing care coordination and anticipatory guidance at a modest cost could reduce later costs by better preservation of ventricular function, management of arrhythmias, and other strategies to prevent or slow secondary disability. It is possible that the dollar cost of a quality adjusted life year for comprehensive health management of adolescents and young adults with CHD might compare favorably with other established uses. In order to accomplish this, the system would have

to provide continuous coverage for all patients *and* create a seamless navigation system to keep patients within the system during a vulnerable period of life when there are many social changes and incomplete development of executive functioning.

The adult CHD community is defining its needs for a network of high-resource centers to serve as a hub for healthcare delivery, a training center for developing an appropriate workforce, and a research consortium for refining treatment protocols and shedding light on the unnatural history of this new and unique population. None of this will happen without presenting a compelling rationale for why our beleaguered society should make this investment. This is a critical time to design a system of health management for adolescents and young adults that is efficient, effective, and integrated with quality management and data systems that allow us to make continual improvements and justify ongoing support by taxpayers and commercial interests.

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