Health Care Policy for Adults With Congenital Heart Disease

The Patient, the Physician, and Society

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A major goal of the pediatric cardiologist is to help the infant born with congenital heart disease to become a productive adult. This goal has become realized in recent decades as, with successful medical and surgical management, over 85% of infants currently born with congenital heart disease can expect to survive to adulthood.1 As we have all known for some time but has only recently become formalized, however, the outcome of care must extend beyond survival into issues of patient satisfaction, well-being, and productivity, as well as continued access to health care. It is in these areas that the growth of our care has not kept pace with the growth of our patients. In the recent Bethesda Conference on Adults with Congenital Heart Disease,2 one of the major concerns raised by the conference was the lack of financing for adults with congenital heart disease. For those of us who take care of these patients, it is difficult to explain the personal distress caused by the problem and the frustration felt by parents, patients, and physicians. I recently received a letter from a parent describing the growth of her child and her current situation, and she allowed me to submit it to Circulation. This letter was especially poignant to me personally in that her daughter was the first patient I cared for in the recovery room when I began my pediatric cardiology fellowship and one that I have followed closely ever since.

A Letter From Jenny’s Mother

I am writing this in an attempt to obtain assistance for my daughter. She was born with a severe heart defect, truncus arteriosus, and has undergone both closed and open heart surgeries. She has been hospitalized for extended lengths of time and has required extensive medical monitoring and testing to ensure that her heart is functioning properly and that her three daily medications are not producing adverse side effects.*

On March 13th, she will celebrate her 21st birthday. On that date, she will no longer be eligible for health insurance coverage under the policies now carried on her. Jenny is currently carried on Blue Cross/Blue Shield of Texas by her father through his place of employment and has CHAMPUS as a secondary coverage under the policy that my husband carries on himself and our family. After her 21st birthday, neither of these policies will continue to cover her. Jenny’s three medications are currently costing us about $30/month with Blue Cross coverage. This cost will jump to approximately $100/month without insurance. The tests she must have periodically are completely out of our financial range. When she loses her insurance coverage, she will, in effect, lose her access to adequate medical care.

For many years, Jenny received financial help with her medical care through the Crippled Children’s Services. Several years ago following my marriage to Jenny’s stepfather, we were informed that because of my marriage and the joint income, Jenny would no longer be eligible for coverage by this agency. I am an elementary school teacher; my salary is $24,000 annually. My husband is a retired NCO of the US Air Force, with a retirement pension of about $9,800 annually. We have three younger children in addition to Jenny, ages 11, 13, and 14. My husband is a full-time student at the local community college, and I am attending graduate school at night in addition to my teaching job.

In anticipation of the financial problems of Jenny’s medical care costs, we applied last fall for Social Security Disability for her, hoping to get her on Medicaid after her private insurance expired. After a lengthy interview, followed by an examination of Jenny by a local adult cardiologist whom she had never met, the Social Security agency decided that she was not eligible for any kind of medical or employment assistance.

She enrolled in the local community college following her graduation from high school. Never a strong student, she struggled through two semesters before becoming so discouraged that she dropped out. As an educator of 20 years, I am convinced that Jenny is probably learning disabled, possibly in connection with her physical disability. We would like to obtain testing for her, to ascertain the problems she has, and possibly generate solutions for these; however, we do not have the financial resources to pursue this.

Following her departure from the college, she began looking for employment. On each of the applications she filled out, there was a space marked “physical disabilities or handicaps.” Being an honest person, she filled in “congenital heart defect.” Jenny is relatively attractive, dresses neatly, and speaks with average coherence. In not one single instance was she asked to return for an interview after completing the application.

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*Medical note: The patient recently had replacement of her pulmonary artery conduit; she has a right ventricular pressure of 55/0–8 mm Hg. She has no physical disability but has palpitations and ventricular tachycardia controlled with antiarrhythmic drugs. She will require at least yearly follow-up.
I contend that these businesses got no further on the application than the blank that labeled her as “handicapped.” These were not all “small businesses”; included in the list are our school district and a major university.

With her lack of success in obtaining a job interview, she went to the Texas Rehabilitation Commission. After an interview, they told her that they had no funds to use for training her, but they could perhaps give her aid in applying and interviewing for jobs in some of the businesses that cooperate with them. Her initial interview with TRC was over 6 months ago. To date, she has not once been contacted about a job.

She faces an acute twofold problem in her life. First and most immediate is her need for adequate health care. The second, less evident problem appears to be psychological. For the last 20 years, she, her family, and her physicians have directed all her energies and talent toward nursing her through a life-threatening illness. Now she is facing the difficult process of moving away from the day-to-day emphasis on her health to that of becoming a productive adult. She is having difficulty focusing her life, setting long-term goals, and learning how to achieve them. Society appears to be using a double standard to judge her. While not “disabled” enough to qualify for government help with her problems, she is still seen by the majority of employers and businesses as too disabled to be of use to them.

I believe that she and others like her have the potential to become productive members of society and to contribute positively to the world they live in. Unfortunately, I don’t think she will be able to realize this potential unless she can find help in various areas. We as her family are willing and ready to do anything we can to help her succeed in the world. We, however, have reached a point where we no longer know what to do nor where to turn. We need help.

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Scope of the Problem

At the present time, there are approximately 400,000 adults in the United States over the age of 21 with congenital heart disease. These numbers are growing at a rate of approximately 5% per year. Fewer than 10% of the survivors are disabled; the remainder are capable of working. Most require continued medical care, and yet one recent study of 5,448 patients estimates that only 22% of those with severe defects have financial coverage for their health care, which poses a serious problem of access to care. Many pediatric and medical cardiologists are continuing to see these people gratis, but as the numbers increase, this solution will become untenable. Many of these problems were presented at a recent American Heart Association Consensus Conference on Insurability of the adolescent and young adult with heart disease.

Problem Formulation

There are several interrelated parts of the problem leading to diminished access. Each one of these is demonstrated in the case presented above. The first is a problem with the patient obtaining work. This can be subtle when the individual patient wants to find work but has not had sufficient job training or job counseling to find the appropriate type of work. Other young adults with congenital heart disease simply do not even look for work. Some of these individuals have been dependent and overprotected as children and require a greater stimulus to seek work, despite the fact that they are not disabled. The second problem rests with the employer. Despite the illegality of discriminating against handicapped individuals, as shown in the case above, no fewer than eight employers, including the school district in which she lived, refused her employment. The third problem is with the insurance companies. After fighting the battle to get employment, these individuals face denial of coverage because of preexisting conditions or, at best, long delays in the initiation of coverage. The fourth problem is with our overall health care system. Most states have programs to fund health care for chronically ill children. These programs were developed at a time when seriously ill children covered by these programs did not survive to adulthood. Now that there is routine survival to adulthood, these individuals, much like Jenny, are covered by a program that suddenly disappears. There are no states with programs specifically designed to continue coverage as these individuals enter adulthood.

A Potential Solution

There are a number of possible approaches to this problem. One approach, which we have proposed and is currently under consideration in Texas, involves job training and counseling for young adults with congenital heart disease. In this program, as long as these individuals are in the job training program, their cardiology care is covered by the state. There are two possible routes for funding through the state: the first is to expand the Chronically Ill and Disabled Children’s Program into young adulthood; the second is to obtain Social Security coverage. In order for Social Security to cover these individuals, the definition of “disability” would need to be changed. We have proposed that, during the period of job training, these individuals be classified as “functionally disabled” because, as a result of their chronic disease, they were ill-prepared to seek appropriate work on their own. The assumption is that the majority of individuals will obtain work and that when they do, a minimal payback (much along the lines of a student loan) is proposed for the next 5 years. We have performed a cost–benefit analysis, with the costs of job training and cardiology care offset by these individuals generating the benefits of state and local taxes when they begin to work and paying back part of this “loan.” We compared this program with the current program, in which Chronically Ill and Disabled Children’s Services cover health care to age 21 and provide no job incentive. The analysis was projected for a 15-year period and, in current dollars, the proposed program provides a positive benefit after cost of $1.7 million more than the present program, because these individuals become productive.

There is one final piece to the puzzle. The program relies on private sector insurance funding for all workers. To ensure this coverage, it would involve regulation of the insurance industry to eliminate preexisting conditions as reasons for uninsurability and would require insurance carriers either to include those with congenital heart disease in a general risk pool or, less optimally, to provide separate rates for those with congenital heart disease that are commensurate with their costs. We have recently estimated the cost of congenital heart disease in the adult at $988 per year between the
ages of 21 and 40. If the carrier added 10% for overhead, the cost of cardiology care would be $1087.7.

We all recognize that this is a Band-Aid for a comprehensive approach to health coverage in the United States. But until this important goal is realized, smaller steps are necessary.

Conclusions

Children with congenital heart disease who become adults with congenital heart disease must have provision made for their health care needs. For those capable of working, a policy should be sought, followed by a transitional program implementation, that will provide an incentive to work and will provide financing for health care. The greatest intangible benefit is that an adult who spent early life dependent on society will be able in later life to contribute to that same society.

References


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