Psychosocial Concerns and Life-Style

MARY E. HAMBURGEN, MD

Dramatic changes in the prognosis of many congenital heart defects have led to the emergence of a new group of adults with congenital heart disease, many of whom had the unique experience of growing up with an illness they were not expected to survive. This feature distinguishes these patients psychologically from most other adults with chronic medical diseases. Nevertheless, few investigators have studied the psychosocial characteristics of these patients. This discussion briefly describes some of the common experiences of the patient with congenital heart disease at different developmental stages and examines potential emotional sequelae. Conclusions are based on available data combined with personal observations in the active postpediatric clinic at our institution.

Children with congenital heart disease and other chronic illnesses have long been considered at risk for psychopathology. Potential emotional sequelae stem from the stressful and frustrating effects of chronic illness on the child's normal activities, the detrimental effects on the self-esteem of perceived difference from peers and the impact of inappropriate parental attitudes and behaviors engendered by the illness (1). Recent evidence indicates that most psychologic issues faced in daily living with a chronic physical illness are not disease specific but, rather, cut across diagnostic categories. Overall, children with chronic illness are 2 to 2.5 times more likely to have significant emotional disturbances than are healthy children (2). Still, more than two-thirds of all children are psychologically healthy and many go on to achieve exceptional personal and professional development despite considerable adversity.

Infancy and childhood. The various aspects of mature psychosocial function require a base that is established during childhood, revised during adolescence and refined in adulthood. The patient with congenital heart disease confronts special challenges, beginning in infancy when difficulty in nursing, decreased vigor and perceived unresponsiveness may cause a mixture of guilt, disappointment, apprehension and irritation in the parents, leading to disturbed parent-child relations. Poor psychologic adjustment in the child has repeatedly been correlated with maternal anxiety and overprotection, whereas the degree of physical incapacity has only a minimal effect on adjustment (3). The presence of congenital heart disease profoundly affects all family members and may lead to emotional problems in siblings (4) as well as increased marital conflict. Memories of family strife may fuel later guilt feelings in the patient.

The school years. Once children with congenital heart disease reach school age, they face the challenge of keeping up academically and socially despite diminished stamina and increased absenteeism. The majority of patients have an intelligence quotient within normal range, but emotional adjustment, independence, motivation and physical vigor also play important roles. The effects on intelligence of cyanosis and circulatory arrest with profound hypothermia remain open to question. Approximately 30% to 40% of chronically ill children have school-related problems despite normal intelligence (5). In contrast, some patients relentlessly push themselves to achieve academically and, later, professionally in an effort to compensate for their perceived or real physical inadequacies.

Relations with peers are an important facet of emotional development during the school years. Congenital cardiac disorders, which limit physical activity, alter appearance, impair sexual development and result in absences from school or work, are almost certain to influence socialization. Feelings of being “different,” lack of self-esteem and fear of social isolation are common psychologic themes, especially in adolescents. For some, memories of loneliness and frustration may linger and affect adult relations.

Adolescence and young adulthood. The lives of patients with congenital heart disease are frequently punctuated by reminders of their fragility and mortality: the anxiety that
this engenders is dealt with in a number of ways, both adaptive and maladaptive. There may be unconscious denial of the seriousness of the illness, a defense especially common in adolescents and accounting for much of their medical noncompliance. Rather than accept the illness and experience the attendant anxiety, they minimize its importance and behave as though they were healthy, not taking their medications, exercising beyond their capacity and missing medical appointments. There is a strong element of rebellion inherent in these actions, with the ill adolescent patient viewing the medical regimen as yet another example of intrusive parental control. Conversely, some teenagers and young adults passively follow the directions of parents and physicians, relinquish control and resist moving toward independence and the adult role.

Other risk-taking behavior involves smoking, consumption of alcohol, drug abuse and irresponsible sexual activity. The frequency of alcohol and drug abuse in patients with congenital heart disease is not known, but early caution serves the purpose of later prevention. Education regarding the special risks of such abuse should begin very early.

Sexual and marital concerns. Clinical experience suggests that most adults with congenital heart disease have normal sexual and marital relations. Still, certain issues may arise. Because of low self-esteem, patients may feel the need to limit their romantic aspirations and pursue only "safe" prospects. Passive dependent patients may seek unequal relations with individuals who wish to assume a "caretaker" role. There may be hesitation in disclosing the illness because of fear of rejection. Sexual issues may arise. Adolescents with congenital heart disease are significantly more concerned about sexuality than are other ill adolescents, with fears of death during intercourse particularly prominent among teenage boys 160.

Marriage raises additional concerns. Men especially may be uncertain about their ability as financial providers. In women, pregnancy and childbirth are significant concerns and fear regarding genetic transmission is common in both men and women. Both patient and spouse may appreciate about the possibility of a shortened life span with subsequent "abandonment" of the family. Marital counseling is often helpful in dealing with these common problems before they become disruptive.

The workplace. Adults with congenital heart disease also face special challenges in the workplace (see Insurability and Employability by Drs. Mahoney and Skorton elsewhere in this conference). Briefly, patients with congenital heart disease are at a disadvantage in the job market, not only because of current physical limitations, but also because of their experiences. If sheltered and overprotected as a child, they must subsequently cope with the effects of experience and cultural deprivation. Job discrimination is common and many feel compelled to conceal their medical history from potential employers. Occupational choice is also somewhat restricted. Despite these difficulties, many adults with congenital heart disease perform extremely well in demanding professions. These patients often report that they were encouraged during childhood to strive to reach their limits and to view their illness as a surmountable obstacle, rather than as a limiting handicap.

References


Insurability and Employability

LARRY T. MAHONEY, MD, FACC, DAVID J. SKORTON, MD, FACC

Life insurance can be obtained for a large proportion of patients with congenital heart disease, particularly after early adolescence. Unfortunately, funding of health care for adults with congenital heart disease remains a major problem. Changes in methods of reimbursement in the health insurance industry have been developed in an attempt to contain the cost of new technologies while making the technologies appropriately available. How patients should be funded to meet the costs was among the major concerns voiced in the Bethesda Conference. If funding for the care of adults with congenital heart disease were less problematic, more cardiologists might be attracted to this field.