Pediatric Heart Transplantation: Transitioning to Adult Care

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There were 9,566 pediatric heart transplants reported to the ISHLT from 1982-2009. Every year, the ISHLT pediatric registry report survival statistics improve and, in addition, the number of children and adults undergoing transplantation for congenital heart disease continues to increase. With increasing numbers of pediatric patients surviving into adulthood with excellent quality of life, more young adult transplant recipients will receive care at adult centers. Transition programs are critical to support care for these young patients who are traditionally cared for at children’s hospitals. Transition is defined as a “complex set of beliefs, skills, and processes that facilitate the movement from pediatric care to adult centered care.” The goal of transition is to provide comprehensive, developmentally appropriate healthcare in a coordinated, uninterrupted, and seamless manner across centers and in partnership with patients.

Transitions from pediatric to adult care occur during a period of vulnerability, characterized by poor judgment and decision-making, risk-taking behaviors, and emotional reactivity, when these young patients are taking on new responsibilities such as 1) leaving home for the first time, 2) pursuing education / jobs, 3) establishing significant personal relationships, and 4) beginning to manage their own healthcare needs. Consequently, these young adults are at increased risk for poor adherence to medical care and subsequently poor health outcomes.

Ringewald et al. reported a high rate of rejection in nonadherent adolescent pediatric heart transplant recipients, which led to a high rate of death in this population. McBride et al. examined outcomes of 20 pediatric heart transplant recipients after transition to adult centers. Patients averaged 15.5 years of age at transplant, and average time to transition was 5.6 years. Survival was 100%, 74%, and 56% at 1, 5 and 10 years after transition to adult care with 6 deaths and 3 patients lost to follow-up. In a recent multicenter registry study of pediatric and adult patients by George et al., including 10,131 patients from 29 institutions in the Cardiac Transplant Research Database (n = 7,368, from 1990 to 2008) and 32 institutions in the Pediatric Heart Transplant Study (n = 2,763, from 1993 to 2008), the highest risk for death from rejection occurred in patients transplanted between the ages of 10 and 30, particularly black females. These findings suggest that in addition to potential clinical factors, adherence may contribute to these alarming findings. This group of patients warrants targeted interventions to optimize medication and clinic adherence and potentially improve outcomes during this vulnerable time.

Programs transitioning children with chronic illnesses to adult systems of care are limited and, in most cases, nonexistent. As noted above, poorly planned transitions for young adults with solid organ transplants may increase the risk of graft failure. Many barriers to a successful transition between pediatric and adult centers exist, including lack of preparation by pediatric providers for transitioning care, lack of adult provider training in meeting the psychosocial and behavioral needs of young patients, lack of time and reimbursement, and lack of a coordinated transfer from pediatric to adult care. Families and patients have reported differences in the culture of pediatric versus adult models and nervousness about going to a new center, placing undue emotional and financial stress on patients and families. These patients may be lost to follow-up after transfer, until a lapse in care contributes to morbidity and emergency room visits.
An excellent report on transitioning care was published last year for adolescents with congenital heart disease regarding “best practices in managing transition to adult centers.” Adolescents have significant gaps in knowledge of their disease, treatment, and self-care, as reported by Sable et al. which is applicable to transplant recipients as well. We must do a better job educating and preparing our young transplant recipients prior to their transition to adult centers.

Transition programs should be implemented between pediatric and adult centers. Components of a transition plan should include education about heart transplantation, self-care (e.g., medications, complications of transplant, lifestyle issues [i.e., heart healthy diet, activities of daily living, exercise, return to school/work, sexual and reproductive health, and avoiding risk-taking behaviors [smoking, drugs and alcohol abuse]], and keeping appointments), the importance of adherence to the medical regimen, and social support to facilitate self-care.

Heart transplant coordinators at pediatric and adult institutions are ideally suited to facilitating a safe transition from pediatric to adult care, with support from pediatric and adult cardiologists as well as mental health professionals. Transition discussions should begin early, ideally between age 14 and 16, with transfer of care some time during the next 5 years. Parents should be included in the transition process, as they transition from being a “care coordinator” to a support role. An improved transition will promote better health outcomes for these young adult transplant recipients, including lower rates of morbidity and mortality after transition.

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