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# Evidence Supporting the Effectiveness of Transition Programs for Youth With Special Health Care Needs



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More than 90% of adolescents and young adults with chronic medical conditions will survive into adulthood. Transitioning from pediatric to adult health care services for these individuals has often times been associated with deterioration of their health and Quality of Life. Separation from their pediatric provider and lack of preparedness of the adult health care system has been identified as major barriers in

preventing the successful transition of these individuals. The purpose of this review is to summarize the available data related to transitioning adolescents and young adults (AYA) with special health care needs into the adult health care system.

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## Introduction

**L**ife expectancy for children, adolescents and young adults (AYA) with congenital, genetic, or acquired chronic medical conditions that previously had resulted in premature death has increased dramatically over the past 50 years. Transitioning from pediatric to adult health care services for these individuals has generally been dependent on age rather than maturity or independence and has often times been associated with deterioration of the health of the AYA. Barriers such as absent or insufficient insurance coverage, insufficient supply of adult health care providers or facilities prepared for or trained to care for this population, and the difference between the supportive, family-centered approach of pediatrics versus the adult-centered model of individual responsibility has added to the challenges of transitioning youth with special health care needs (YSHCN) into the adult health care system.

Differentiating improvements due to the provision of services/processes versus development of new medications and therapies is difficult when dealing with the population of YSHCN as they transition into the adult health care system. Most of the literature includes

descriptive reports and the population does not lend itself to randomized controlled studies of the transition process. Most recommendations for transition programs are based on expert opinion or single-center nonrandomized studies. The purpose of this review is to summarize the available data related to transitioning YSHCN into the adult health care system. Included are literature reviews of transition of patients with four specific illnesses (cystic fibrosis, sickle cell disease, congenital heart disease, and cancer) and one Cochrane Review of four randomized controlled trials.

## Disease Specific Transitioning

### *Cystic Fibrosis*

Previously a disease limited to childhood, the Cystic Fibrosis Foundation (CFF) now estimates that almost half of patients with cystic fibrosis (CF) in the United States are older than 18 years of age.<sup>1</sup> Additionally the CFF estimates that the median age of survival for a patient with cystic fibrosis is approximately 39.3 years of age. In anticipation of the improved outcomes resulting from advances in health care and medical technology the CFF mandated, in 1996, that CF centers develop programs to transition patients to adult providers by 21 years of age in order to maintain accreditation.

In 2008, McLaughlin et al.<sup>2</sup> surveyed the 195 CF care centers in the United States where more than 85% of patients with CF are followed regarding their

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transition practices. The study found that the process of transitioning was beginning at approximately 17 years of age on average and that only about half of the programs were providing a medical summary prior to transfer. The study did find that many programs were providing counseling on smoking, substance abuse, and dieting. As a result, the CFF emphasized the importance of introducing the process of transition at an earlier age (12–13 years) and the necessity of establishing nationally recognized age-specific goals for transitioning into adult care.

The CFF believe that several processes have been identified that appear to be important in successful transition. These include

- 1) Making the transition to adult care a gradual process,
- 2) Remembering that parents are going through a transition as well, and
- 3) Working together to improve transition.<sup>3</sup>

A review by West and Mogayzel<sup>3</sup> indicated several factors among the population of CF patients that are associated with a successful transition. These are

- 1) Buy-in from both the pediatric and adult teams,
- 2) Creation of a transition program that begins early in adolescence,
- 3) Establishment of a transition meeting for pediatric and adult providers to discuss individual patients, and
- 4) Creation of a transition clinic or other venue where members of the adult team can meet patients and their families before the actual transfer of care.

### *Sickle Cell Disease*

The prevalence of sickle cell disease (SCD) in the United States is estimated to be approximately 70,000–100,000 and in about 1 in 400 individuals of African descent.<sup>4</sup> Between 1910 and the year 2000 there has been a dramatic increase in the life expectancy of persons with SCD, from less than 5 years of age to almost 45 years of age, with most of the increase occurring since 1970.<sup>5</sup> Most of the longevity can be attributed to advances in medicine, including the early introduction of antibiotics and vaccinations, along with the use of medications and transfusions to decrease the incidence of ischemic episodes.<sup>6</sup>

At the present time recommendations for transitioning AYA with SCD into the adult health care system are based on expert opinion or single-center non-randomized studies.<sup>6</sup> In 1994, Telfair et al.<sup>7</sup> published the first study related to transitioning AYA with SCD into adult health care. They found that AYA were primarily worried about how they would pay for services and how they would be treated in the adult health care system. Parents were primarily concerned about issues related to individual responsibility and independence and the subsequent ability to cope with adult care. In 2009, McPherson et al.<sup>8</sup> reported that there was an inadequate level of preparation for AYA with SCD in anticipation of transitioning into adult services. Almost 10 years later no consensus metrics have been developed or validated for the transition of SCD patients from a pediatric to an adult health care team.<sup>6</sup>

### *Congenital Heart Disease*

Today more than 1 million adults in the United States are living with a congenital heart disease (CHD). Less than half of these adults are being seen by appropriately trained providers and a minority is being seen in specialty adult congenital heart disease clinics. In 2011, the American Heart Association (AHA) published a scientific statement with recommendations on transitioning AYA with CHD into adult centered care.<sup>9</sup>

Recommendations included issues related to:

- 1) Social/family dynamics: Impact of chronic illness as related to CHD,
- 2) Health supervision issues,
- 3) Residual surgical issues,
- 4) Electrophysiology/pacemaker issues,
- 5) Sexuality, pregnancy, and reproductive issues,
- 6) Exercise prescription/rehabilitation,
- 7) Education and career choices, and
- 8) Insurance (Health and Life).

Almost all of the recommendations were classified as having a significant benefit compared to risk but almost all lacked any supporting data and were based on either consensus opinion of experts, case studies or published standards of care. The authors of the Statement acknowledged that “the development of ideal transition programs is a laudable goal that may not be achievable in the current healthcare environment”.<sup>9</sup> The AHA recognized that a diverse group of providers can be

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