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Transitioning the Adolescent With Type 1 Diabetes Mellitus

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Transition to adult-care services is an important milestone for all youth with chronic illnesses. When older adolescents with type 1 diabetes mellitus have reached an age when it is no longer appropriate to receive care from a pediatric team, the transition to adult-care services can be problematic and, in certain cases, may result in loss of medical follow-up. Patients with diabetes should take an active role in the management of their disease. The importance of good metabolic control for the immediate well-being of the patient and for reducing the risks of chronic complications is well established. Regular follow-up within a trusting and collaborative patient-provider relationship is of prime importance for obtaining adequate metabolic control (Pacaud, Yale, Stephure, Trussell, & Davies, 2005).

Diabetes is one of the most common chronic diseases in children and adolescents; approximately 151,000 people below the age of 20 years have diabetes. When diabetes strikes during childhood, it is routinely assumed to be type 1 diabetes and each year, more than 13,000 young people are diagnosed. Three-quarters of all cases are diagnosed in individuals less than 18 years of age. The prevalence of type 1 diabetes mellitus among U.S. residents aged 0–19 years is 1.7 per 1000 (American Diabetes Association, 2010; Centers for Disease Control [CDC], 2010).

The issue of transitioning adolescents to an adult care program has been a concern for clinicians and researchers from a variety of subspecialties. Families who have already experienced this period of transition highlight concerns related to poor communication between families and providers. Two large population-based surveys with sample sizes of 5500 and 4000, respectively, found that only half of the parents ever discussed their child's changing needs, and

only 30–42% discussed transferring care to an adult provider (Weissberg-Benchell, Wolpert, & Anderson, 2007).

Adolescents and emerging adults with diabetes express similar concerns regarding communication and the difference in the tenor of adult and pediatric practices. In a study done by Eiser et al. (1993), patients perceived vast differences between pediatric and adult programs, with pediatric models being family centered, more informal, and socially oriented. Adult programs were perceived as more formal, with an emphasis on the risks of long-term complications. Teens seem to prefer programs that are more developmentally sensitive to their unique needs. Dovey-Pearce et al. (2005), found that emerging adults with type 1 diabetes wanted the following in their diabetes medical care: continuity of contact with medical provider(s), clinicians who try to integrate the patient's life circumstances into recommendations for diabetes care, and developmentally tailored care (Weissberg-Benchell et al., 2007).

Clinicians have multiple concerns about transitions as well. Telfair et al. (2004), assessed provider perceptions regarding transition services, and although most agreed that transition programs were necessary, few incorporated guidelines to facilitate the transition process. Those who care for both adolescents and adults expected to see the patient with their parent, whereas those who cared only for adults expected to see the adolescent alone. Pediatric providers worry about the quality of adult care services available to the patients. This concern translates to outcomes, as it appears that when pediatric providers express skepticism regarding access to quality care, transition is impeded. Pediatric providers' concerns regarding their patients' access to adult providers and insurance coverage also impact their participation in transition planning. Clinicians who treat only adults also express discomfort with treating adolescent and emerging adult patients. Adult

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providers may be uncomfortable caring for unfamiliar populations and desire specific training on the unique needs of young adults. In addition, they require teaching materials that are geared to young adults/adolescents (Weissberg-Benchell et al., 2007).

Complications can be expected when the active transfer phase has not been smooth, and adolescents have expressed feeling of fear and abandonment. After reviewing the transition literature covering more than 30 chronic illnesses over the past 20 years, Reiss and Gibson (2002) found that most adolescents demonstrated a problem keeping appointments with adult providers. Missed or irregular appointments following the change to adult health care system were not only common but also associated with diabetes-related complications, crisis intervention for diabetic ketoacidosis, or higher glycosylated hemoglobin levels (Rapley & Davidson, 2010).

Without a good transition plan, the adolescent with type 1 diabetes mellitus can experience a sense of disengagement from healthcare. In addition, they may become confused and disillusioned with the adult-care system. They often have no specialist follow-up and seek prescriptions through the primary care physician. The primary care physician is generally not able to provide the education and ongoing support for management of type 1 diabetes mellitus in adults. Among the many factors contributing to poor transition are that older adolescents and young adults are more likely to not attend diabetes appointments and, most importantly, they have not been prepared for transition. Often “transfer” occurs rather than transition (McGill, 2002).

Transition should be a purposeful, planned movement of a young person from child-centered to adult-oriented health care systems. A significant number of critical issues impact on the success of transition. The young person should feel involved and that they have control over their destiny. Transition should occur at a time of stable health and at an age not too old or too young for their culture and society. The literature states that the best age to begin transition is 10 years (McGill, 2002). Preparation should include a more directed focus on diabetes self-management skills for the teen/emerging adult and his or her parents. There should be a gradual transfer of diabetes care responsibilities to the teen from the parent or guardian. Broadening responsibilities go beyond diabetes management tasks such as glucose monitoring and insulin administration and should include scheduling appointments and ensuring a proper supply of medications and supplies. Diabetes education should be redirected to the growing and developing teen rather than focused exclusively on the parents. Adolescents should be evaluated and educated without a parent in the room. Preparation for adult care should include information about the differences between pediatric and adult providers in their approaches to care, as well as education regarding health insurance and how to maintain coverage (Peters & Laffel, 2011).

The pediatric provider should prepare and provide to both the patient and future adult care provider a written summary that includes an active problem list, compilation of medications, assessment of diabetes self-care skills, summary of past glycemic control and diabetes related comorbidities, as well as a summary of any mental health problems and referrals during pediatric care. Health care providers need to recognize the vulnerability of emerging adults with diabetes to loss of consistent health care and difficulties in adhering to diabetes management due to competing psychosocial, educational, and vocational changes, leading to deteriorating glycemic control. Both pediatric and adult care providers should assist in providing links to resources that could benefit the patient (Peters & Laffel, 2011).

The transferring health care providers should provide emerging adults with specific referrals to adult care providers versed in the principles of intensive diabetes management to match the particular needs of the patients with type 1 diabetes. One might consider the creation of a directory of adult providers with expertise and interest in the care of young adults. Consideration should be given to assisting the young adult with scheduling the first appointment with the adult care provider within 3 to 4 months of the final pediatric visit; a care ambassador or patient navigator can aid the transitioning young adult with follow-up to ensure timely visits (Peters & Laffel, 2011).

Screening guidelines for microvascular and macrovascular complications in pediatric and adult patients with diabetes should be followed. Assessment of risk for macrovascular complications should begin in childhood according to guidelines for lipid screening, blood pressure assessment, and weight management. Birth control, pregnancy planning and risks, prevention of sexually transmitted diseases, use of alcohol and drugs, smoking, and driving should be discussed with older teens and the emerging adults by both pediatric and adult providers with an emphasis on the interplay of these issues with diabetes. Both pediatric and adult providers should ensure that their patients with diabetes, or with any chronic illness, receive ongoing primary and preventive health care and that the emerging adults feels that they are receiving accessible, patient-centered, coordinated, comprehensive, continuous, compassionate, and culturally effective care (Peters & Laffel, 2011).

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