Transition of Diabetes Care from Pediatrics to Adulthood

By Sobha Kollipara, MD and Francine R. Kaufman, MD

Introduction

Adolescence is a stage of life filled with unfamiliar experiences. It is also the stage when youth separate from their parents and acts of rebellion and coping problems often emerge. The young person is striving to become an adult and learn the intricacies of adulthood. Having diabetes at this age adds to the challenges. In addition to diabetes self-care transition, other life events complicate the move into adulthood, such as high school graduation, employment, relationships, independence, and moving away from the security of home. These adolescents need proper direction and support by various groups of people to effect a successful transition. Traditionally, healthcare professionals and parents provide this support. School nurses can play a significant role in helping adolescents prepare for transition during their school interactions.

Adolescence and Diabetes Care Transition

During adolescence, diabetes control is often suboptimal. This is due to both physiological and psychological factors. From a physiological standpoint, adolescence is associated with insulin resistance due to the dramatic change in growth hormone secretory dynamics. Insulin resistance causes blood glucose levels and insulin requirements to increase (Amiel et al., 1986; Dunger, 1992). From a psychological perspective, youth want to assume self-care, but they often fall short without adequate parental supervision. This means that the period of transition to adulthood is more challenging for the adolescent with diabetes. Adding even more to the challenge is the fact that youth who have had diabetes for more than a decade are at the stage when diabetes complications begin to develop, particularly if their diabetes has been poorly managed. How this transition period is handled, therefore, is critical for short- and long-term physical and mental health. At times, moving to adult care with increased self-care responsibility can be the medical equivalent of high-risk behavior for some adolescents. In our own clinical experience, some adolescents who have transitioned to adult care are naïve about potential diabetes complications and do not adhere to medical recommendations. Others seek medical care only for acute crisis interventions and consequently do not establish a strong bond with adult care providers.

While an optimal transition care plan might be considered essential, existing data suggest that in most cases a prearranged plan has not been put in place (Flemming et al., 2002). The International Society for Pediatric and Adolescent Diabetes (ISPAD, 2002) states in their guidelines for adolescent diabetes care: "Although the majority of adolescents adapt well to the difficult challenges of puberty, it must be recognized that their health care and emotional needs are distinctly different from those of younger children or older adults."

Existing Strategies

The traditional model

In the traditional model, the transition of responsibility for diabetes care from the parent to the adolescent/young adult is abrupt. Often the youth who relies on his or her parents for advice on how much insulin to take and when to take it, securing medications and supplies, and for making diabetes-related appointments is abruptly given responsibility for these diabetes tasks when he or she leaves home and/or graduates from high school. This young adult goes from being told what to do, to having to figure it out alone. The shift from dependence to independence is often confusing and something for which the young adult may not be prepared or emotionally ready to accept. At the same time, diabetes care providers are changed — instead of a pediatrician and a pediatrics-focused diabetes team, the young adult is under the care of an internist or family medicine team. Insurance coverage is often changed or lost as the young adult is no longer covered by his or her parents or a state entitlement program designed for children. The whole approach to diabetes care changes and focuses on the individual (Bryden et al., 2001; Howard et al., 2001), who may not be adequately prepared for self-management or independence.

Newer strategies

Many centers and clinics are designing plans to provide an optimal transition for young adults. Information from surveys and follow-up of young people in adult care shows that important consideration needs to be given to many factors that affect successful transition (Busse et al., 2004; Kipps et al., 2002; Visentin et al., 2006). The following are some of the approaches used.

- Establish young adult clinics with joint coverage by both pediatric and adult providers.
- Introduce adult care providers to adolescents while they are still under pediatric care, to promote a comfort level for the patient and family.
- Prepare adolescents. Tell them what the process of transition will be, with a time line, well ahead of

the actual transfer. Preparation is the key to success.
- Involve nurses in follow-up of new young patients in the adult clinic.
- Use the age of 17 to 18 only as a guide and not a standard. Consider the patient's psychological and social maturity as a guide for readiness.
- Consider coinciding transition with high school or college.

Diabetes transition and school nurses

School nurses provide a vital role in health care of adolescents before they graduate from high school. School nurses oversee day-to-day health maintenance of students while at school, support students with diabetes, and provide health and wellness education. Although the role of school nurses has never been studied in models of successful transition, intuition strongly suggests incorporating school nurses into the diabetes-care transition. Reinforcement of good diabetes self-care and independence during the high school years will help build the adolescent's knowledge and confidence.

Outcomes of some transition models

The difficulties with transition are not unique to any specific country, but global. Currently there are follow-up survey data from some young adults in different countries at various medical facilities (clinics, medical centers, and hospitals) (Bryden et al., 2001; Busse et al., 2007; Kipps et al., 2002; Visentin et al., 2006), some with adequate transition plans and others without. The results indicate that:
- After transition there is a decline in clinic attendance,
- Many young adults repeatedly change their adult healthcare providers,
- There is an increase in A1C and diabetes morbidity in some centers,
- There is higher attendance if the adolescent met the adult team prior to transition.

An appropriate target age for transition appears to be 18 to 20 years. There are more positive results when there is effective collaboration between the pediatric and adult clinics, and when a formal pretransition education program is in place.

Challenges and Barriers to an Effective Transition

As adolescents become young adults they often "drop out" of medical care. It appears that for some, the healthcare system is not equipped to provide the kind of diabetes care that fits their needs. Hence, many people in this age range become the "forgotten group." This is aggravated by the fact that obtaining health insurance is often difficult for young adults. Following are some issues that affect the interactions of adult care providers and young adults and negatively impact the effective delivery of diabetes care.

Challenges for the adult care providers:
- Many care providers may have a poor understanding of the adolescent's emotional and psychological needs and abilities.
- There is often inadequate interaction and follow-up between the care provider and the young adult.
- Providers of adult care may not understand the issues that lead to nonadherence to diabetes care needs in young people, such as time and financial constraints and school and work issues.
- The transfer of medical record information from the pediatrician to the adult care giver is often inadequate.

Challenges for the young adult:
- Social distractions, such as employment, higher education, and relationships;
- Emotional barriers – fear of leaving home, loss of parental support, and loss of security;
- Lifestyle factors and inability to adjust to the demands of diabetes management and social pressures;
- Lack of familiarity with and confidence in the adult care provider;
- Conflict between greater autonomy and dependence;
- Lack of adequate knowledge for optimal diabetes self care.

Recommendations

1. ISPAD's guidelines for optimal transition are (ISPAD, 2002):
- Include negotiation and liaison between pediatric and adult services and, when possible, organize the clinics jointly.
- Decide on the optimal age and stage of development for transition to joint care or transfer to adult care based on local services and agreements.
- Prepare the adolescent for transfer in advance.
- Ensure that there is no hiatus in care at the time of transfer and that the young person is not lost to follow-up care.

Recommendations from others:
- Transition should be gradual and organized.
- Transition should occur when the health of the adolescent is stable and after independent health care and diabetes self-care behaviors are understood.
- There should be sensitivity to the emotional maturity and coping abilities of the adolescent.
- Psychosocial support may be necessary.
- A team approach helps the successful transition to young adult.
- If possible, there should be joint clinics and a coordinator at the adult clinic.

Strategies for School Nurses:

During high school years, the school nurse should stress the need for independence as students reach the transition period. To encourage adolescent independence in diabetes care, the school nurse could:
- Observe and help the student to make independent decisions about diabetes care at school;
- Encourage the student to follow healthy behaviors and avoid high-risk behaviors;
- Help the student cope with social and peer pressures that interfere with diabetes care at school;
- Recognize the need and refer to:
  - appropriate healthcare professionals if diabetes management is suboptimal,

- psychosocial professionals and resources if coping skills are inadequate;
- Reinforce good habits for improvement in diabetes control;
- Help parents to shift the responsibility to the student.

Summary

Transition to adulthood for young people with diabetes is a critical milestone in their lives. It is a time when many facets of life are changing simultaneously. It is most important to recognize the special needs of adolescents with diabetes during this period. A successful and smooth transition of diabetes care should be based on a well-organized plan that includes the young person and the family. The process should be facilitated by collaboration between the pediatric and adult clinics. It should be guided by structured policies and guidelines, including posttransition evaluation. Finally, it should be a process, not an event. The school nurse can play a critical role in its success.

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