In Brief
This article reviews risk factors for poor clinical outcomes in young adults with type 1 diabetes, describes a developmental framework through which to approach young adults, and offers guidance for diabetes providers on tailoring their clinical approach to fit young adult patients' life circumstances and readiness to engage in self-care behaviors.

Identifying the Unique Needs of Transition Care for Young Adults With Type 1 Diabetes

Katharine C. Garvey, MD, and Howard A. Wolpert, MD, Guest Editors

During the transition from adolescence to young adulthood, patients with type 1 diabetes must learn to independently manage their condition during a life stage that is often fraught with competing priorities and developmental challenges. For pediatric and adult health care providers who care for young adults with type 1 diabetes, the following are key items on the clinical agenda:

1. Identify risk factors for poor clinical outcomes and intervene therapeutically as indicated
2. Assess the young adult's developmental stage and barriers to self-care and individualize treatment goals accordingly

Diabetes Outcomes in Young Adults

Before the era of intensive insulin therapy, the prognosis for young adults was often poor. Bryden et al.\(^1\) reported data on a cohort of young adults in the United Kingdom with baseline assessment during 1987–1988 at a mean age of 22 years and follow-up assessment during 1999–2000 at a mean age of 35 years. During this time, there was no significant improvement in A1C, and the proportion of severe complications increased from 3 to 37%; multiple complications were more common in women.

In general, diabetes outcomes have markedly improved with the advent of intensive insulin therapy. For example, in a recent analysis of long-term complications throughout 30 years for subjects in the original Diabetes Control and Complications Trial (DCCT) cohort,\(^2\) the cumulative incidences of any proliferative retinopathy and nephropathy were 21 and 9%, respectively. By comparison, the authors cite that the 25-year cumulative incidences of proliferative retinopathy and nephropathy were 40–53 and 35%, respectively, in cohorts of patients that developed their diabetes 10–20 years before the subjects in the DCCT.

However, despite such improvements, intensive management during adolescence does not always translate into optimal glycemic control in young adulthood, as illustrated by follow-up data from adolescent participants in the DCCT. At the end of the DCCT, there was a statistically significant difference in A1C levels between the intensive treatment (mean A1C 8.06%) and the conventional treatment (mean A1C 9.76%) adolescent groups. Four years after the DCCT was completed, the mean A1C of subjects from the original adolescent intensive treatment cohort (now aged 27 ± 2 years old) had increased to 8.4% and was not significantly different from follow-up A1C data in the conventional treatment group.\(^3\) Thus, equipping adolescents with good diabetes self-management skills alone is not sufficient to ensure optimal glycemic control during the transition to independent diabetes care.

Young adults with type 1 diabetes are at increased risk for early mortality. A case-control analysis from the Diabetes U.K. Cohort Study\(^4\) indicated that a number of psychosocial
factors, including previous psychiatric referral, living alone, and a history of drug abuse, were associated with acute diabetes-related deaths in young adults. In this study, low socioeconomic status correlated significantly with mortality from chronic causes. Likewise, in data from Sweden, although socioeconomic status was generally higher, an impressive 58% of 159 deaths in a cohort of type 1 diabetic patients aged 15–34 years were diabetes-related.

Increased awareness of substance abuse in young adults with type 1 diabetes is imperative. The overall prevalence of substance abuse has ranged from 10 to 29% in studies of adolescents and young adults with type 1 diabetes and is likely underreported. Importantly, illicit drugs can lead to sympathetic overactivity (cocaine, amphetamines), hyponatremia (ecstasy), and excess carbohydrate intake (marijuana) and have been shown to precipitate ketoacidosis.

Disordered eating, particularly in women, is another key consideration and has been related in several studies to the development of microvascular complications in type 1 diabetes. For example, in a cohort study of 91 young women with type 1 diabetes, disordered eating and insulin omission or under-dosing to lose weight increased during the 5-year study period, and the risk of retinopathy was significantly greater in the setting of these behaviors. In an 11-year follow-up of 234 women with type 1 diabetes, 30% reported purposeful insulin restriction at baseline, and this behavior was associated with a three-fold risk of death after adjustment for age, BMI, and A1C.

Taken in aggregate, the above outcomes findings, many of which are from longitudinal follow-up studies, highlight the necessity of addressing risk behaviors in clinical encounters with young adults with type 1 diabetes. In evaluating young adult patients, providers should consider whether the above risk factors contribute to poor glycemic control and arrange for appropriate intervention and specialty care. In addition, as discussed in the following section, it is important for diabetes care to be tailored to patients’ developmental stage.

Developmental Framework

The term “emerging adulthood,” first proposed by developmental psychologist Jeffrey Arnett, describes the “early” young adulthood period, generally from late teens to mid-20s. This early adulthood stage is typified by competing educational, social, and economic priorities; avoidance of responsibility; feelings of invincibility; and rejection of “adult” control or advice, all of which can limit receptiveness to change. In contrast, “late” young adulthood, which generally begins in the late 20s to early 30s, is characterized by independent decisions, beliefs, and values; financial independence; and acceptance of full responsibility for oneself.

Although the developmental distinction between the early young adult phase and the late young adult phase certainly does not apply to all patients, it is a valuable guide for diabetes providers seeking to meet the needs of this vulnerable population. For early young adults with diabetes, normal developmental struggles are further complicated by the complex daily demands of diabetes care, such as monitoring blood glucose levels, administering insulin, adjusting for food and exercise, and accessing appropriate medical care and diabetes supplies. Many early young adults are often unwilling to take responsibility for these tasks and actively participate in their diabetes management; as a result, there is often a mismatch between the realities of life at this stage and the expectations of providers and parents. Transfer to adult diabetes care, possibly with providers who are less aware of developmental perspectives and diabetes outcomes in mind, providers should seek to identify barriers to self-care in young adult patients. Prior research, although limited, provides some guidance in this regard. In one study utilizing focus group and interview methods, college students with type 1 diabetes reported multiple barriers to successful diabetes management, including time management difficulties, stress, hypoglycemia, diet management constraints, and inadequate finances. Along similar lines, in a small survey study of college students with 45 respondents, irregular schedules, diet, hypoglycemia, and finances were also reported as barriers to glycemic control, along with peer pressure and lack of parental involvement, whereas an increased sense of responsibility was felt to improve glycemic control. Weight concerns and body image are additional factors that were not prominent in these data but are clearly critically important. Another factor to consider is that, for young adult patients, a legacy of unrealistic perfectionist goals from past diabetes providers may set the stage for diabetes burnout.

Transition Versus Transfer

While health care “transfer” refers to the actual physical movement of patients from pediatric to adult care services, the broader concept of “transition” also encompasses the development of independence, responsibility, and active participation in diabetes self-management. Studies in Canada and Europe, where transition age is generally mandated, have established the presence of important difficulties in the transfer process. These include significant delays between last pediatric and first adult clinic visit, prolonged loss to follow-up, decreased number of post-transfer annual diabetes visits, and increased risk of diabetes-related hospitalizations. In addition, patient comments highlight feelings of aloneness, lack of preparation, and perceived differences between pediatric and adult care cultures.

In light of these findings, given that the developmental and schedule demands of early young adulthood may be a distraction from forging ties to new diabetes providers, it may be appropriate on a case-by-case basis to delay transfer from pediatric to adult diabetes care, if possible.

Guidance for Diabetes Providers Caring for Young Adults

For both pediatric and adult providers on either side of patient transition or transfer, clinical evaluation during the earlier phase of young adulthood should focus on identifying barriers to optimal self-care that are individualized to the patient. However, the overriding priority for patients at this life stage is to ensure continuous diabetes care and clinical follow-up, given that poor clinic attendance has been linked to poor diabetes outcomes. Care should include annual...
eye examinations and urine microalbumin measurements and counseling about coping with the impact of diabetes on relationships, contraception, smoking, prevention of alcohol-induced hypoglycemia, risks of binge drinking, and sick-day management. In counseling patients, emphasis on making diabetes “more manageable,” rather than on “improving control,” will likely be more productive.10

In terms of patient expectations for clinical encounters, in a survey study of young adults with type 1 diabetes in Canada,22 75 respondents prioritized subjects of interest. Interestingly, topics on the “standard” agenda for a clinic appointment, such as intensive diabetes management, insulin delivery devices, and carbohydrate counting, were only selected by about 40% of respondents. More popular selections included goal-setting with the health care team (71%), stress management (59%), what’s new in diabetes research (79%), sex/pregnancy (53%), financial issues (48%), and alcohol and drugs (45%).

Another key area of consideration for early young adults is parental anxiety about their child’s passage to independence. It is often necessary for providers to advise the family of young adult patients about realistic expectations for self-care and glycemic control at this life stage. Overly intrusive or controlling parents can undermine a young adult’s self-confidence and motivation; this has been termed “miscarried helping” in the literature.10

Older patients in the late young adulthood phase are generally independent, more receptive to improving self-care, and at a stage where they are forming permanent relationships. Providers caring for patients at this stage should continue to address the social context and keep in mind that life partners can be significant agents of change.

A key theme that underlies all care recommendations for young adults is the need for providers to foster self-efficacy (i.e., belief in one’s capabilities to achieve a goal or outcome) in their patients. Notably, self-efficacy has been found to be predictive of self-care behaviors as well as glycemic control in young adults with type 1 diabetes.23

Conclusions

Young adults have unique needs that often do not fit into the typical agenda of pediatric or adult diabetes care. Multiple studies point to the high risk of poor diabetes-related outcomes in this age-group, but these outcomes have not been consistently linked to particular aspects of the health care transition. There is a great need for more research to 1) explore the association between transition characteristics and self-care, glycemic control, and quality of life for young adults with type 1 diabetes and 2) study the clinical effectiveness and cost-effectiveness of different models for supporting patients through the transition from pediatric to adult care.

Because transition programs are not yet widespread in the United States, however, providers in the meantime must arm themselves with a working knowledge of available outcomes data and a solid understanding of the developmental phases and challenges of young adulthood. It is our hope that, as research and creation of uniform guidelines are in the pipeline, diabetes providers will take the time to reflect about their care of young adults. Diabetes care and teaching should be tailored to foster the development of self-efficacy and work with individual young adults’ landscape of life demands and readiness to engage in care.

References


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*Katharine C. Garvey, MD, is a fellow in pediatric endocrinology at Children’s Hospital Boston, and Howard A. Wolpert, MD, is senior physician in the Section of Adult Diabetes at the Joslin Diabetes Center in Boston, Mass.*