

Transitioning From Pediatric to Adult Care

A new approach to the post-adolescent young person with type 1 diabetes

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Diabetes research and health care have traditionally been divided into two distinct areas for receiving medical care: pediatric and adult. We propose a fresh approach to providing care in which we consider the period of development after high school as a period of “emerging adulthood” for youth with diabetes. We argue that the traditional conceptualization of only two distinct groups of patients misses the unique personal needs of individuals immediately post–high school. We frame this discussion about the needs of these post–high school patients (~18–30 years of age) within the context of a contemporary theory of post-adolescent development. With this developmental context in hand, we then review psychosocial research on youth with type 1 diabetes. Next we discuss current clinical perspectives and knowledge about the natural course of diabetes during these years. Armed with an understanding of development, psychosocial functioning, and overall health, we then consider the literature regarding transition programs for youth with chronic diseases—both diabetes and other illnesses. We conclude by presenting specific strategies and recommendations to help both pediatric and adult providers care for the transition needs of this vulnerable population of individuals with diabetes.

An updated theory of the developmental period after adolescence

Over the past century, traditional developmental psychology defined the time immediately after adolescence as the

“young adult period” (3,4). In contrast, a leading contemporary developmental theorist (1,2) has argued that young adulthood does not begin until youth are in their late twenties or thirties and that the developmental stage between ~18 and 25 years defines a period called “emerging adulthood.” Recent cultural trends in America for young people in their twenties lead to delays in assuming adult roles with respect to marriage, parenting, and work. Arnett (2) suggests that today’s young people

“explore the possibilities available to them in love and work, and move gradually toward making enduring choices . . . This period is a time of anxiety and uncertainty, because the lives of young people are so unsettled, and many of them have no idea where their explorations will lead. They struggle with uncertainty even as they revel in being freer than they ever were in childhood or ever will be once they take on the full weight of adult responsibilities.”

Arnett’s cross-cultural findings (2) indicate that the length of this developmental period may vary among different cultures and societies. For example, members of minority groups may be less likely to experience their late teens and early twenties as a period of emerging adulthood, as they may have fewer opportunities for this “exploration.” Arnett also reports that socioeconomic status (SES) may be more important than ethnicity, as young people in the middle or upper SES brackets have more opportunities for these explorations than peers from lower SES backgrounds.

Moreover, in developing countries, emerging adulthood may be experienced more by youth in urban areas than youth in rural areas.

Although societal, cultural, and SES differences exist, it is our position that Arnett’s theoretical model provides a valuable framework for understanding the issues that the majority of youth with type 1 diabetes in the U.S. confront in the post–high school period. An understanding of this psychologically complex phase of exploration may help diabetes researchers and clinicians recognize the unique needs of this cohort of patients, thus allowing them to better match their approach with a young person’s life circumstances and readiness to become an active participant in his/her own diabetes management.

Arnett first studied individuals between the ages of 18 and 24 years and asked them what attributes made someone an adult. Three specific achievements were cited: 1) the ability to accept responsibility for one’s self, 2) the ability to make independent decisions, and 3) the ability to become financially independent. Interestingly, in a representative sample of individuals aged 18–30 years from multiple ethnic and income backgrounds in the U.S., most did not believe that they had achieved these goals (2).

In the first phase of emerging adulthood, immediately after adolescence, there is a desire for independence, yet also a fear of independence. Freedom from parental supervision and rules also brings responsibilities that can be quite daunting. Youths may be managing rent, finances, relationships, and career choices, while receiving less help from their parents and experiencing less structure in their daily routine. If the youth has moved away from their hometown, she/he is making these decisions in a place removed from close friends. Thus, during the first period of emerging adulthood, the youth may be transitioning geographically, economically, and emotionally away from the parental home. During the later phase of emerging adulthood, typically in the years between 25 and 30, there is often a maturing sense of identity and more “adult-like” roles in society, such as a stable intimate relationship or employment.

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Abbreviations: DCCT, Diabetes Control and Complications Trial; SES, socioeconomic status.

A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.

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Psychosocial research with youth with type 1 diabetes after adolescence

Emerging adults with diabetes face even more complicated decisions than their healthy peers. The daily demands of diabetes care (including the need to coordinate daily care, finding appropriate care providers, and the daunting task of access to appropriate supplies and medical care) must be woven into all of the normative choices regarding relationships, occupations, living arrangements, and financial management. The following review of empirical behavioral studies of post-adolescent youth with type 1 diabetes illustrates two ideas central to this discussion: 1) that the developmental period after high school represents a distinct period with unique demands separate from adolescence, and 2) for a subgroup of high-risk adolescent patients, there is continuity between the diabetes-specific adherence and control problems of adolescence with youth's adherence behavior and glycemic control status over the past-adolescent years. The earliest psychosocial studies of post-adolescent youth (aged 18–25 years) with type 1 diabetes identified a delay in psychosocial maturation (5–9). It is important to remember that the majority of patients on whom these empirical studies were based experienced their childhood and adolescent years with diabetes during the period before the Diabetes Control and Complications Trial (DCCT), i.e., before the era of intensive management of type 1 diabetes.

More recent empirical studies that were carried out in the post-DCCT era have reported findings that contradict these earlier reports of delayed psychosocial maturation in post-adolescent youth with type 1 diabetes. Pacaud et al. (10), in Canada, studied the psychosocial maturation of individuals 18–25 years of age with type 1 diabetes and age-matched control subjects who did not have diabetes. The authors concluded that youth with type 1 diabetes did not differ from healthy peers in terms of psychosocial maturation. Interestingly, there was a tendency for respondents in both groups to score lower than the norm on indexes of responsibility and independence. This study supports Arnett's theory that youth do not begin to assume the traditionally more "adult" roles until they are in their late twenties (2). Similarly, Gillibrand et al. (11) recently studied young people 16–25 years of age with type 1 diabetes living in the U.K. and also found that

emerging adults with diabetes have normal levels of psychosocial maturation. They also found that a high level of family support was the strongest predictor of adherence to the diabetes regimen.

While the cross-sectional studies of Pacaud et al. (10) and Gillibrand et al. (11) documented the normal psychosocial maturation of young adults with type 1 diabetes, the longitudinal cohort research of Bryden et al. (13), in the U.K., identified a subgroup of young adults with disordered eating (insulin misuse for weight management), especially in female adolescents with type 1 diabetes. Disordered eating was strongly related to the development of microvascular complications and mortality among the young adult women (13,14). Bryden et al.'s (13) 8-year follow-up study of a cohort of adolescents with diabetes found that behavioral problems at baseline were a predictor for poorer glycemic control in young adulthood and a significant increase in serious microvascular complications (15). During the follow-up evaluation of the young adults, 54% of the women were overweight (BMI >25.0 kg/m²), up from 21% at baseline. This weight gain can be an important factor contributing to poor ongoing diabetes self-management and adherence. More than 35% of adolescents and young adult women with type 1 diabetes in the U.K. acknowledged intentional reduction or omission of insulin to control weight (14).

Similar conclusions about the continuity of adherence and glycemic control problems over the late adolescent/early adult years have been reported by Wysocki et al. (17) in a cross-sectional study of 18- to 22-year-olds with type 1 diabetes. Subsequently, Bryden et al. (18) published a report that followed a group of young adults 17–25 years of age over an 11-year period into adulthood. There was no improvement in glycemic control over this period. The proportion of patients having serious complications increased over this period, and women were more likely than men to have multiple diabetes complications. Psychiatric symptoms in late adolescence and young adulthood predicted psychiatric problems later in the cohort.

In conclusion, the most recent psychosocial research has documented that the majority of post-adolescent youth with type 1 diabetes in the post-DCCT era do not demonstrate delays in psychosocial maturity. Studies have documented, however, that post-adolescent patients have unique and specialized needs with

respect to their diabetes care during the vulnerable and transitional period after high school. Moreover, there is a subgroup of adolescent patients with type 1 diabetes, especially females, who are at increased risk for the downward cycle of mental health problems (especially disordered eating), poor glycemic control, and the development of microvascular complications. Longitudinal follow-up studies of adolescent patients have indicated that for this subgroup of youth at high risk for the interrelated problems of poor control, psychiatric problems, and diabetes complications, these problems only worsen over the late adolescent and emerging adulthood years.

Type 1 diabetes during the past-adolescent period

The unique needs of emerging adults with diabetes described above pose a challenge to both pediatric and adult care systems, as these individuals fall outside the focus of the neatly divided pediatric and adult tracks (19). The standards of medical care developed by the American Diabetes Association include specific recommendations for several special population groups (including children and adolescents, pre-conception, and older individuals) (20); however, these guidelines make no mention of the special needs of young adults with diabetes or of the need to consider behavioral and developmental issues in the evaluation and treatment of the young adult patient.

Young adults with diabetes are a high-risk group. As highlighted by the follow-up data from the DCCT (21), the demands and challenges of the young adult phase of life can detract from a focused commitment to diabetes care. Four years after completion of the DCCT, the cohort who had entered the trial as adolescents were young adults (mean age 26 years) with a mean A1C of 8.4%, similar in both the conventional and intensive groups (22). In contrast, at this stage following the completion of the trial, the adult cohort (mean age 38 years) had mean A1C values of ~8.0% (22). It is noteworthy that individuals who were in the intensive treatment arm of the DCCT had poorer glycemic control as young adults than as adolescents. These findings indicate that intensive care of adolescents with diabetes does not necessarily set the stage for optimal glucose control during young adulthood and underscore the need for focused interventions to help

young adults successfully cope with the transition to independent self-care.

Young adults with diabetes face a significantly increased risk for premature morbidity and mortality. The British Diabetic Association Cohort Study found that in the 20- to 29-year age-group, mortality is increased threefold in men and sixfold in women compared with the general population (23). Acute complications were the major cause for mortality in this age-group, with 68% of diabetes-related deaths being certified as due to hypoglycemia and ketoacidosis (24). Further study of this cohort has identified that several psychosocial factors, including living alone, past drug abuse, and a history of psychiatric referral, are significant contributors to this increased mortality from acute diabetes-related events (25). Population-based studies from Scandinavia also indicate that acute metabolic complications are the most common cause for death in the age-group <30 years and also show an association with alcohol/drug misuse and mental illness (26–28). From 30 years of age onwards, cardiovascular disease is the predominant cause for death in individuals with type 1 diabetes (29). This risk for accelerated macrovascular disease in young adults with diabetes underscores the importance of early treatment of dyslipidemia and hypertension, as well as intervention to assist patients with smoking cessation (30).

The microvascular complications of diabetes may present during the young adult period, and screening for these complications is an important focus of the follow-up visits of these patients. Data from the nationwide Diabetes Incidence Study in Sweden, which registers all new diabetes diagnoses in the 15- to 34-year age-group, indicate that 6% of the cohort diagnosed with type 1 diabetes in 1987–1988 had incipient or overt nephropathy (i.e., micro- or macroalbuminuria) 10 years later (31). The same follow-up study reported that 5% had moderate nonproliferative retinopathy and 2% proliferative retinopathy 10 years after diagnosis (32). Other studies involving young adult populations have shown a higher prevalence of eye disease. Maguire et al. (33) reported that in an Australian young adult cohort with type 1 diabetes, 15% had a history of moderate retinopathy and 10% a history of severe retinopathy requiring laser treatment (33). A U.K. study of young adults with type 1 diabetes in poor glycemic control found that 34% had background retinopathy, 8% had preproliferative ret-

inopathy, and 25% had undergone laser therapy (18).

Clinical implications. These studies highlight the important clinical issues and high-risk behaviors that should be addressed by the clinician caring for the emerging adult with diabetes. Evaluation of these individuals should include specific attention to: 1) identifying factors, such as alcohol and drug abuse and mental illness, that lead to neglect of self-care tasks and increased mortality from acute metabolic complications; and 2) screening for early microvascular complications. A major imperative of the clinician is to ensure that the young adult patient continues to follow-up with regular medical visits. A nonjudgmental and supportive approach by the clinician can be critical in ensuring ongoing follow-up and making the young adult feel comfortable about acknowledging substance abuse and insulin restriction.

Geddes et al. (34) studied the adequacy of diabetes care during the period when young adults with type 1 diabetes are in a university environment in the U.K. These authors noted that youth who maintained frequent contact with the health care system and made greater use of intensified insulin therapy did not improve their glycemic control while attending a university, most likely due to lack of attention to dietary habits and glucose monitoring, and concluded that young adults with type 1 diabetes need more specialized care for managing diabetes during the university years. Mellinger (35) has outlined practical issues that need to be addressed in preparing students with diabetes for life at college. Important issues that deserve special consideration include alcohol (which is a major factor contributing to hypoglycemia in the college age-group), sexual health, and having a sick-day diabetes management plan. College students with diabetes identify several factors that can be barriers to optimal self-care, including time constraints, erratic schedules, food choices, concerns about hypoglycemia, and absence of social support (36). Motivators for improved diabetes control cited by this age-group tend to be short-term issues, in particular feeling better physically and being able to participate in normal activities with their peers. Communication between the health care professional and the young adult patient focused on identifying the individual motivators for improved control and the life issues that detract from a commitment to diabetes

management is the foundation for developing realistic treatment plans and goals and the underpinning for a smooth transition to independent self-care.

Transitioning between pediatric and adult care

The issue of transitioning adolescents and emerging adults to an adult care program has been a concern for clinicians and researchers from a variety of medical specialties. Families who have already experienced this period of transition highlight concerns about poor communication between families and providers. Two large population-based surveys with sample sizes of 5,500 and 4,000, respectively (37,38), found that only half of the parents ever discussed their child's changing needs with the physician, and of those who did discuss the changing needs, only 30–42% discussed shifting care to an adult provider. Adolescents themselves reported that they did not receive adequate information regarding transition issues (39), and they worry about leaving their familiar health care team for an unknown medical provider.

Adolescents and emerging adults with diabetes express similar concerns regarding communication and the difference in overall tenor between adult and pediatric practices. In a study by Eiser et al. (40), 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 (41). Dovey-Pearce et al. (42) 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. Both Dovey-Pearce (42) and Court (41) recommend developing clinics where pediatric and adult providers can be seen at the same clinic. They also recommend facilitating a developmental framework when caring for this unique population.

The difficulties inherent in successful transitions for individuals with diabetes have also received attention in the literature. Pacaud et al. (43,44) surveyed patients with diabetes who had been transferred from a pediatric diabetes clinic to an adult clinic. The findings of

these two surveys almost a decade apart were the same: 31% of the adolescents had a lapse of over 6 months between their last pediatric visit and their first adult visit, with 11% lost to follow-up. Many patients believed that their transition was abrupt, that they lacked information about resources, and that it was difficult to coordinate all of the subspecialties they needed to see (e.g., endocrinologist, dietitian). Similarly, Kipps et al. (45) assessed patient perceptions regarding transition experiences. Although 90% transitioned to adult services at 17 years of age, only 61% regularly attended an adult care program 2 years posttransfer.

Clinicians have multiple concerns about transitions as well. Telfair et al. (46) assessed provider perceptions regarding transition services, and although most agreed that transition programs were necessary, few did anything 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 (47–49). This concern translates to outcomes, as it appears that when pediatric providers express skepticism regarding access to quality care, it impedes transition (50). Pediatric providers' concerns regarding their patients' access to adult providers (51,52) and their concerns about their patients' access to funding and insurance coverage (52,53) also impact their participation in transition planning.

Clinicians who treat only adults have also found multiple barriers to feeling comfortable with treating adolescent and emerging adult patients. For example, adult providers express concerns about caring for conditions that they are not familiar with (47,51,53,54) and desire specific training on the unique needs of adults with chronic illness that began in youth (51,54,55), as well as teaching materials that are specifically geared for young adults/adolescents that can be used in their clinics (54,55).

Despite the many existing transition programs around the world, only two programs actually assessed the outcomes of their targeted transition programs. McDonagh et al. (56) studied a transition program for young adults with Juvenile Idiopathic Arthritis, and Van Wallegghem et al. (57) studied a program for young adults with type 1 diabetes. In the McDonagh study, the pediatric group

worked closely with adult care providers and hired a program coordinator to orchestrate the transition. They developed an individualized transition plan in collaboration with the young adult and parents. These plans included issues regarding health, home, and school. The goal was for the adolescent to evaluate their readiness for transitional care by evaluating their own knowledge, skills, and awareness of resources. These individualized plans were introduced by the pediatric team as a way of identifying areas that would need addressing over the next year or two so that transition was presented as a gradual process.

The Van Wallegghem (57) study assessed the feasibility and acceptability of an innovative transition service initiated to serve 18- to 30-year-olds with type 1 diabetes as they transitioned between pediatric and adult care in Manitoba, Canada. The "Maestro" service identified and coordinated access to appropriate support services in the community for young adults with type 1 diabetes. The Maestro or "health navigator" was an administrative coordinator who maintained telephone and e-mail contact with the young adults to help them identify barriers to accessing appropriate adult health care services. A comprehensive array of communications channels was established: a Web site, a bi-monthly newsletter, drop-in informal patient educational dinner events, and patient discussion/support groups. Over the first 2.5 years of the project, 79% of eligible patients participated in the program, requesting assistance for both access to care and educational programs. In addition, results indicated that this model of service was feasible and very acceptable for young adults with type 1 diabetes as they transition from pediatric to adult care.

The McDonagh (56) and Van Wallegghem (57) studies highlight the importance of a programmatic effort in facilitating the transition process by working with the patient and family to link them to a variety of clinical and educational resources. Two smaller yet similar studies confirm these results. One study assessed young adults with solid organ transplant (48), and the other assessed young adults with diabetes (49). These studies highlighted the importance of discussing transition at an early age, providing written materials supporting the discussion, and facilitating collaboration among pediatric and adult care providers.

Guideline development

The need to develop guidelines to facilitate the implementation and success of transition programs has been recognized by professional organizations. In 2002, a policy consensus statement by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians—American Society of Internal Medicine (58) noted that the goal of an effective transition plan is to provide developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. Similarly, in 2003, the Society of Adolescent Medicine (59) published a position statement that recognized the vital importance of organized and coordinated transition programs. These statements offer guidelines for successful transition programs, aimed at facilitating uninterrupted, comprehensive, and accessible care. For example, it is recommended that health care providers partner with the young adult patient, the adult care providers, and the young adult's family. The importance of obtaining ongoing education for all stakeholders (patients, providers, and families) regarding the core knowledge and skills required to provide a developmentally appropriate health care transition has also been recognized. Written transition plans, completed in collaboration with adolescents aged 14 years and older and their families, should be developed and should include information regarding the specific health services needed, who will provide them, and how they will be financed. This plan should be reviewed and updated annually and should include discussions regarding continuous health care insurance coverage, taking into consideration the costs of transition planning and care coordination. Finally, the statements recognized the need for collaborative development of "best practices" for the management of adults with diseases of childhood (58,59).

It is our position that the special needs of the emerging adult with diabetes fall outside the focus of the current health care system. Epidemiology studies show that a subset of the young adult population with diabetes is at high risk for accelerated microvascular complications and death from acute metabolic decompensation and that psychosocial issues are a major underlying risk factor. Furthermore, follow-up data from the DCCT indicate that intensive treatment during adolescence does not necessarily set the stage for optimal glucose control

Table 1—Recommendations for facilitating the transition process from pediatric to adult diabetes care provider

Pediatric providers	Adult providers
Universal recommendations	
Facilitate family and social supports for daily diabetes care tasks. Assess for disordered eating. Assess for alcohol and/or drug history. Assess for history of mental health services. Develop “transition” clinic days, where pediatric and adult providers meet patients and their families at the same time. Develop ongoing educational programs for providers regarding transition issues.	Facilitate family and social supports for daily diabetes care tasks. Assess for disordered eating. Assess for alcohol and/or drug history. Assess for history of mental health services. Develop “transition” clinic days, where pediatric and adult providers meet patients and their families at the same time. Develop ongoing educational programs for providers regarding transition issues.
Discipline-specific recommendations	
Hire a “transitions coordinator” to facilitate transition. Develop telephone and e-mail contact with young adults to facilitate transition plans. Develop a Web site or newsletter that provides information regarding access to services and funding. Collaborate with patients and their families to develop an individualized written transition plan ~2 years prior to the transition date. The written plan should include: <ol style="list-style-type: none"> 1) an assessment of the patient’s knowledge and skills 2) information regarding adult care providers and how to access those services 3) information regarding access to funding/insurance coverage after age 18 years. 	Screen for early microvascular complications. Obtain/develop teaching materials that are developmentally appropriate for adolescents and young adults.

during young adulthood. These findings underscore the importance of considering behavioral and developmental issues in the evaluation and care of the young adult patient with diabetes.

The needs of emerging adults require a multifaceted program aimed at addressing the needs of this particularly vulnerable and important population of individuals living with diabetes. A number of important organizations have published recommendations regarding the development of transition plans for individuals leaving their pediatric providers and moving toward adult care providers. We believe it is incumbent upon the American Diabetes Association to develop clinical care guidelines covering young adults as an important first step in putting the spotlight on the unique needs of this special patient group and providing practical guidance for health care professionals. Our review of the existing literature suggests that the evidence base guiding the clinical care of the young adult with diabetes is limited, although clinical guidelines do exist regarding transition issues for this population. Based on the existing guidelines and empirical studies we reviewed in this article, we offer a set of recommendations (Table 1) to help both pediatric and adult providers care for the transition needs of this vulnerable population of individuals with

diabetes. Although these guidelines are a summary of the current knowledge, there remains a pressing need for research to examine the medical, psychosocial, and cost-effectiveness outcomes of different models for transitioning care from pediatric to adult medicine and to identify potential strategies for engaging young adult patients in self-care.

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