

## In Brief

This article reviews research related to living with depression and diabetes in the post-high school and young-adult periods. Clinical lessons for pediatric and adult diabetes care providers are distilled from this evidence base.

# Living With Depression and Type 1 or Type 2 Diabetes in Late Adolescence and Young Adulthood: Lessons From Research

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This article addresses research related to living with depression and diabetes in the post-high school and young adult periods. Attention is given to data-based, contemporary developmental approaches to the developmental tasks in the period after high school, from ages 18 to 30 years. Clinical lessons are distilled from this evidence base separately for pediatric and adult diabetes care providers, and suggestions are given for successful transitioning of youth with diabetes from pediatric to adult care systems.

**Developmental Tasks of the Older-Adolescent and Young-Adult Periods**  
The years immediately after high school are a complex time developmentally. Although this period after high school has traditionally been called “young adulthood,” J.J. Arnett, a leading contemporary developmental theorist, has argued that young adulthood in the 21st century does not begin until young people are in their late 20s or early 30s.<sup>1,2</sup> According to Arnett, the developmental stage between ~ 18 and 28–30 years of age defines a period in the 21st century that is more appropriately called “emerging adulthood.”

Recent cultural trends in America for young people in their 20s lead them to delay assuming adult roles with respect to marriage, parenting, and work. Arnett suggests that, “To be a young American today is to experience both excitement and uncertainty, wide-open possibility and confusion, new freedoms, and new fears.”<sup>2</sup>

To illustrate this delay in assuming adult roles, there has been a consistent delay in the typical ages for marriage and parenthood during the past half-century. In 1950, the median age for marriage in the United States was just under 20 years for women and 22 years for men. In contrast, in 2000, the average age for marriage was 25 years for women and 27 years for men. Similarly, from 1950 to 1970, most married couples had their first child in their very early 20s, whereas in 2000, most couples were waiting until at least their late 20s before becoming parents.<sup>2</sup>

Moreover, data from the 2000 U.S. Census tell us that 56% of men and 43% of women between the ages of 18 and 24 years still lived at home with their parents. Another 30% of men and 35% of women in this age-group lived with roommates. Only 4% of individuals in this age-group lived alone.<sup>3</sup> Therefore, the assumption that individuals in this age-group are independent young adults seems false, both from an historical perspective and also from a fact-based perspective regarding where and with whom individuals in this age-group live.<sup>2</sup>

Arnett and other contemporary developmental theorists subdivide the post-adolescent period of “emerging adulthood” into two phases: an early phase corresponding to the years immediately after high school (~ 18–22 years of age) and a later phase when more traditional adult roles are assumed (~ 23–30 years of age). This age division is somewhat

arbitrary and may not apply to all individuals. Moreover, depending on cultural and family traditions, not all older adolescents progress through the post-high school years according to these two phases. However, conceptualizing the post-high school years as consisting of two phases provides a valuable framework when considering how living with diabetes may further complicate this complex developmental period. This division also may help to ensure that clinicians' approach and focus are appropriately matched to emerging adults' life circumstances and readiness to become active participants in their own diabetes management.

### First phase of emerging adulthood

Levinson<sup>4</sup> and Arnett<sup>2</sup> have theorized that, in the United States, there frequently is a misfit between the developmental tasks of individuals after high school and the expectations of the various institutions responsible for them. Immediately after high school, older adolescents often feel both a desire for and a fear of independence. Freedom from parental supervision and rules brings responsibilities that can be quite daunting. After high school, young people begin to ask themselves questions such as: How do I find/keep a place to live, begin to earn a real income, pay my bills, manage credit, choose a career, and begin a relationship that might be "forever"?

While young people are trying to balance all of their new freedoms and responsibilities, they are probably doing this with less help from their parents and less structure in their daily routines. In addition, young people who have moved away from their home town are making these decisions in places removed from their closest friends and family and possibly where they know very few people.

Arnett suggests that individuals in this first phase are beginning to "explore the possibilities available to them in love and work and move gradually toward making enduring choices. Such freedom to explore different options is exciting . . . However, it is also a time of anxiety and uncertainty."<sup>2</sup>

Arnett suggests that these explorations also lead young people to feel unsettled because they do not yet know where their explorations will lead. For young people who have

transitioned to a college or trade school, their new life will be marked by many new changes, distractions, and demands. During this period that Levinson<sup>4</sup> called the "early adult transition," many 18- to 22-year-old young people are transitioning geographically, economically, and emotionally away from their parental home and have entered a period of exploration and uncertainty.

### Second phase of emerging adulthood

During the second phase of emerging adulthood (typically between the ages of 23 and 30 years), individuals start making more concrete plans about their future life. There is often a maturing sense of identity and adoption of more "adult-like" roles in society, such as a stable intimate relationship, employment, financial independence, and often parenthood.

According to Levinson<sup>4</sup>, only in their late 20s—and not in the late-adolescent years or the early 20s—do young people begin to make permanent choices about adult roles and more permanent decisions about a stable residence, the type of employment they will pursue, and their choice of a life partner.

### Unique Challenges Facing Emerging Adults Living With Diabetes

Emerging adults with type 1 or type 2 diabetes face even more complicated decisions than their peers without diabetes. The daily demands of diabetes care, which include the need to coordinate daily management tasks and the daunting task of finding appropriate care providers and paying for appropriate supplies and medical care, must be integrated into all of the other normative choices regarding relationships, occupations, living arrangements, and financial and health insurance management.

More specifically, after high school, many young people with diabetes face the following unique challenges:

- Relocation away from their parental home
- An abrupt change in diabetes care providers, which may involve transitioning from a pediatric multidisciplinary care paradigm to an adult care model
- A distinct shift in relationships with parents and siblings
- A dramatic change in diabetes-specific responsibilities, including managing health insurance,

ance, securing and financing diabetes medications and supplies, and scheduling and paying for medical appointments

- A change in social/peer support systems, which may create the need to educate many new people about diabetes and diabetes management in college, workplaces, and interpersonal relationships
- A more unstructured daily life than the time-bound daily routines of high school, which may make it much more difficult to maintain daily diabetes care routines

It is important to remember these added transitions, as well as the multiple normative developmental demands of the post-high school period.

For most young people living with type 1 or type 2 diabetes during the first phase of emerging adulthood, competing educational, economic, and social priorities detract from a focused commitment to diabetes management. Consequently, for young people who have had diabetes for many years, it may be unrealistic to expect them to intensify their glycemic control, learn pump therapy, or even transition to a new adult diabetes care provider in this first phase of emerging adulthood. This early phase is often marked by feelings of anxiety as well as invulnerability and a tendency to reject perceptions of adult control. When diabetes is added to this developmental context, it further limits receptiveness to change.

During the second phase of emerging adulthood, however, there may be a growing recognition of the importance of striving for better glycemic control and more receptiveness to improving self-care behaviors. Life partners can be important supports and agents for change, and a shared sense of investment in the future will often catalyze improvements in self-care behaviors.<sup>5</sup>

This later period, when lifelong patterns of behavior are set, can be a crucial window of opportunity for diabetes care and educational interventions.<sup>5</sup> Diabetes care providers and educators have a crucial role at this stage in preparing young people for assuming more self-management responsibilities and facilitating their motivation to achieve improved glycemic control.

### Research on Depression in Older Adolescents and Young Adults

The experience of feeling down or “depressed,” which is commonly used to describe occasional times of feeling stressed, sad, or “blue,” is often confused with major depressive disorder (MDD), a serious psychiatric condition. Unfortunately, MDD is a common, debilitating, and often chronic illness. MDD is a medical diagnosis that involves clusters of mental symptoms (e.g., sadness, loss of interest, and irritability) and physical symptoms (e.g., fatigue, sleep difficulties, and dramatic changes in appetite) that occur daily for at least 2 weeks and significantly impair social, occupational, and school functioning, as well as quality of life. Depression is treatable with medications and/or therapy; however, most people with depression do not receive even minimally adequate treatment.<sup>6</sup>

According to the most recent data from the National Center for Health Statistics,<sup>6</sup> depression is more common in females, non-Hispanic black people, and people living below the poverty line. Unfortunately, rates of depression were not reported separately for the 18- to 30-year-old age-group in these data.<sup>6</sup>

With respect to the continuity of depression during the transition from older adolescent to young adult, Rao et al.<sup>7</sup> studied only females and documented a continuity of adolescent depression during the transition to adulthood. Investigators who studied both sexes have estimated that ~ 75% of young adults with psychiatric disorders first had a diagnosis between the ages of 11 and 18 years.<sup>8,9</sup> More recently, Copeland et al.<sup>10</sup> reported that adolescent depression significantly predicted young-adult depression and that this effect was accounted for by the comorbidity of adolescent depression with other serious adolescent psychiatric disorders such as oppositional defiant disorder, substance abuse disorders, and generalized anxiety disorder. In summary, we know that MDD in adolescents often occurs along with other serious psychiatric disorders and that adolescent psychiatric disorders including MDD frequently predict young-adult disorders.

### Research on Depression in Post-High School Young People Living With Diabetes

#### Depression and type 1 diabetes

Evidence regarding the prevalence of psychopathology in adolescents with type 1 diabetes is contradictory, with some studies documenting increased prevalence of psychopathology compared to adolescents in the general population<sup>11–14</sup> and others finding no higher prevalence of psychopathology in adolescents with diabetes than in the general population of adolescents.<sup>15,16</sup> Some studies have reported a depression prevalence rate of two to three times that in the general population of adolescents,<sup>17</sup> whereas the more recent SEARCH for Diabetes in Youth multicenter study<sup>18</sup> reported that the incidence of depressed mood in adolescence with type 1 diabetes is no higher than that in the general population of healthy adolescents.<sup>19</sup>

The variation among studies of the prevalence of depression in adolescents with type 1 diabetes may be the result of differences in study design, diagnostic or screening instruments used, and diagnostic or cut-off criteria employed.<sup>20</sup> However, recent reports consistently document that the presence of psychopathology in adolescents with diabetes is associated with poorer glycemic control<sup>21,22</sup> and increased incidence of hospitalizations,<sup>23,24</sup> and this puts them at increased risk for diabetes-related complications.<sup>25</sup>

Longitudinal cohort research of Bryden et al.<sup>26</sup> in the United Kingdom identified a subgroup of young adults with disordered eating (insulin misuse for weight management), especially females with type 1 diabetes. This disordered eating was strongly related to the development of microvascular complications and mortality among the young adult females in this cohort. This 8-year follow up study of a cohort of adolescents with diabetes found that behavioral problems during the adolescent years predicted poorer glycemic control in young adulthood and a significant increase in serious microvascular complications.<sup>26</sup>

During the follow-up evaluation, 54% of the young adult females were overweight (BMI > 25.0 kg/m<sup>2</sup>), up from 21% at baseline. Weight gain can be an important factor contributing to poor ongoing diabetes self-management and adherence. More than 35%

of adolescent and young adult females with type 1 diabetes in the United Kingdom acknowledged intentional reduction or omission of insulin to control weight.<sup>27</sup> Rydall et al.<sup>28</sup> also followed a group of adolescent females with type 1 diabetes and found high rates of microvascular complications in the young women with disordered eating behavior.

In the U.K. longitudinal study,<sup>26</sup> psychiatric disorders including MDD at baseline predicted higher A1C levels across the 8-year study period, indicating that psychiatric disorders including depression during later adolescence significantly influenced glycemic control during the young adult period.<sup>16</sup> Subsequently, Bryden et al.<sup>29</sup> published a report that followed a group of young adults 17–25 years of age during an 11-year period into adulthood. There was no improvement in glycemic control during this period. The proportion of patients having serious complications increased during this period, and females were more likely than males to have multiple diabetes complications. Psychiatric symptoms in late adolescence and young adulthood predicted psychiatric problems later in the cohort. Similar conclusions about the continuity of adherence and glycemic control problems over the late-adolescent and early-adult years have been reported by Wysocki et al.<sup>30</sup> in a study of 18- to 22-year-old young people with type 1 diabetes.

In summary, the most recent psychosocial research has documented 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 an increased risk for the downward cycle of mental health problems (especially disordered eating and eating disorders), poor glycemic control, and the development of microvascular complications of diabetes. Longitudinal follow-up studies of adolescent patients have indicated that for this subgroup of young people at high risk for the interrelated problems of poor control, psychiatric issues, and diabetes complications, these problems only worsen throughout the late adolescent and emerging adulthood years.

### Depression and type 2 diabetes

The recent SEARCH study<sup>19</sup> documented that the risk of depression in adolescents with type 1 diabetes is about the same as that in adolescents without diabetes. In contrast, young people older than 10 years of age with type 2 diabetes have a much higher risk of moderate to severe depression than their counterparts with type 1 diabetes (18 vs. 5% in boys; 20 vs. 9% in girls, respectively).<sup>19</sup> Depression is also more than twice as common in adolescents with type 2 diabetes who have a comorbidity such as hypertension and is associated with about 0.5% higher A1C levels.

This study also shows that lower income, non-Caucasian race/ethnicity, lower parental education, and having only one parent are associated with a higher risk for depression. Even when adjustments are made for these variables, males with type 2 diabetes have about a 3.4-fold higher risk of moderate to severe depression than males with type 1 diabetes. Comorbidities increased the risk of depression 1.6-fold in males and 2.67-fold in females. From the available adult and pediatric data, it is not clear which comes first, depression or diabetes. The current thinking is that there is a bidirectional relationship.<sup>31</sup>

Findings from the Third National Health and Nutrition Examination Survey, a population-based health survey of more than 6,000 adults between the ages of 17 and 39 years, revealed that women but not men with a history of a major depressive disorder were twice as likely to have metabolic syndrome than those with no history of depression.<sup>32</sup> This means that clinicians who take care of adolescents with type 2 diabetes should have a high index of suspicion for depression. Because depression is associated with higher A1C levels, depression treatment may be an important part of improving glucose control. It is also important to note that, in addition to a higher rate of depression, young people with type 2 diabetes have lower health-related quality of life scores than young people without diabetes or those with type 1 diabetes.<sup>33</sup>

Because the higher prevalence of type 2 diabetes in adolescence is a relatively recent phenomenon, there are as yet no longitudinal studies of the continuity of depression between the older-adolescent and young-adult years. However, when the multisite

clinical trial called Treatment Options in Diabetes Type 2 for Adolescents and Youth (TODAY) is completed in 2011, we will have some of the first longitudinal data on the clinical course of depression in a large, well-characterized cohort of adolescents with type 2 diabetes followed for up to 6 years.<sup>34</sup> Moreover, we do know from a meta-analysis of controlled studies by Anderson et al.<sup>35</sup> that depression occurs in adults with type 1 or type 2 diabetes about twice as frequently as it does in similar samples of adults without diabetes.

In summary, we cannot yet address questions about the impact of adolescent depression on health or psychiatric outcomes in young adults with type 2 diabetes. However, we do know that depression in older adolescents with type 2 diabetes frequently co-occurs with poorer levels of metabolic control and other physical complications such as hypertension, liver, and kidney problems.

### Lessons From Depression Research for Pediatric Care Providers of Adolescents With Diabetes

The years after high school are a psychologically complex developmental period. Therefore, it is helpful for young people with diabetes and their parents to anticipate the process of transitioning care to an adult provider with a staged approach. Comprehensive and useful materials on this staged approach to transitioning young people with type 1 diabetes will be available in late 2010 from the National Diabetes Education Program at the National Institutes of Health ([www.ndep.nih.gov](http://www.ndep.nih.gov)).

Following is an example of the staged approach to transitioning:

- About 3 years before a young person's high school graduation, someone on his or her pediatric multidisciplinary diabetes team should introduce the idea of transitioning to adult care depending on the young person's plans and the institution's policies. (Some pediatric facilities require all patients to transfer to adult care when they reach the age of 18 years; others have a more flexible policy for continuing to provide care for college-age students.)
- At subsequent medical visits, the pediatric provider should work with the parent(s) and young person to identify essential diabetes

tasks for which the young person currently has no responsibility (e.g., understanding insurance policy language and benefits, making medical appointments, refilling prescriptions and making sure that prescriptions have not expired, and maintaining supplies for a blood glucose monitor or insulin pump.)

- The provider should work with the patient and his or her parent(s) to develop a gradual plan of transitioning these responsibilities to the patient. Care should be taken to ensure that the young person continues to receive enough support and guidance to handle diabetes-specific tasks while also managing the busy life of a high school student who may also be involved in multiple other peer-based activities.

In addition to aiding in young patients' transition to self-care, providers should maintain a high index of suspicion for depression in adolescents with diabetes, especially when there are reports of sudden loss of interest in activities (such as sports or friends) or when a young person experiences a dramatic worsening of academic grades, family relationships, or glycemic control. Pediatric diabetes care providers need to develop a relationship with a mental health care provider (psychologist, psychiatrist, or social worker) in the community who is experienced in working with adolescents with diabetes and their families and can share in the care of young people with diabetes who also have or are suspected of having serious mental health problems (e.g., depression and eating disorders). These problems require a team approach, involving both diabetes care and mental health care providers.

Mental health specialists can provide help with diagnosing and treating mental health issues in adolescents with diabetes. Adolescents with diabetes for whom there is any suspicion of depression should be referred to a mental health expert for diagnosis and, if needed, treatment planning.

In summary, psychiatric disorders in older adolescents with diabetes—especially those with type 1 diabetes—predict poor control, continued psychiatric problems, and health complications from poor glycemic control in the young adult years.<sup>26,27</sup> Therefore, it is crucial to provide diagnosis and treatment for

depression and other mental health problems as early as possible for youth with diabetes during the high school and post-high school years.

### Lessons From Depression Research for Adult Medical Care Providers of Young Adults With Diabetes

Young people with type 1 diabetes may be transitioning geographically, emotionally, and socially during their post-high school years. It is, therefore, important for their adult diabetes care providers to understand the normative demands and distractions these young people may be confronting that may pose realistic barriers to diabetes care.

In *Transitions in Care: Meeting the Challenges of Type 1 Diabetes in Young Adults*,<sup>5</sup> Wolpert et al. point out that the focus of care for type 1 diabetes may need to be on “ensuring that the young adult has continued medical follow-up with annual urine microalbumin measurements and dilated eye examinations and counseling concerning issues such as sick-day management, coping with the impact of diabetes on relationships, contraception, smoking, preventing alcohol-induced hypoglycemia, and the risks of binge drinking.” Wolpert et al. also advise that priority should be given to “establishing a strong relationship based on acceptance and mutual respect to ensure 1) continued follow-up and 2) influence that over time can be directed to promote improvements in self-care behavior . . . and that the fundamental role of the adult health professional in diabetes care is to serve as the patient’s guide in making informed choices about living with diabetes . . .”<sup>5</sup> The authors conclude by emphasizing that, because “adolescents and young adults are usually very sensitive to issues of control and personal autonomy, therefore, highlighting your recognition that responsibility and control belong to the patient can be very helpful in establishing a collaborative relationship . . .”<sup>5</sup>

As is true for pediatric diabetes care providers, adult clinicians caring for young adults with diabetes must maintain a high index of suspicion for depression and develop a relationship with a mental health provider in the community who is experienced in working with young adults with diabetes and depression. Because of the comorbidity of depression and physical complications in adults with

diabetes, early diagnosis and treatment of depression are imperative for optimal health outcomes.

In summary, the years following high school represent a vulnerable developmental period for all youth that is further complicated by the presence of type 1 or type 2 diabetes. Both pediatric and adult diabetes clinicians who care for post-high school-age youth need to be attentive to the possibility of depression in their patients, as depression can contribute to a vicious cycle of adverse psychiatric and diabetes-related health problems. It is especially important for clinicians caring for post-high school youth with diabetes to partner with a mental health professional who can provide both diagnosis and treatment for depression.

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